Formative research

Reducing preventable child deaths from pneumonia, diarrhoea and newborn complications in Timor-Leste

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Front cover photograph – Mother and daughter, Ermera Lama, Ermera District, Timor-Leste.

Executive summary

Background

Successful interventions have been undertaken to advance countries towards their Millennium Development Goal 4 (MDG 4), reducing child mortality. Yet, 6.6 million children under five died in 2012, mostly from preventable diseases, including pneumonia (17%) and diarrhoea (9%). Simple, inexpensive treatments are available for each of these conditions, yet too few children receive appropriate and timely care, particularly in high burden countries and in the most deprived settings due to a range of interrelated factors. In addition, worldwide percentages of neonatal deaths have increased and data shows that a growing proportion of infant mortality occurs at or around the time of birth – a clear sign that child survival efforts must focus on the precarious first month of life.

'Committing to Child Survival: A Promise Renewed', is the global movement to end preventable child deaths that emerged from the Child Survival Call to Action convened in June 2012. Timor-Leste has signed 'A Promise Renewed' pledge that calls for a targeted approach to focus on under-served populations and the residual burden of preventable child deaths.

Although Timor-Leste has reached its MGD 4 targets to reduce child mortality, there continues to be wide intra-provincial disparities. UNICEF East Asia and Pacific Regional Office (EAPRO) commissioned formative research to inform integrated programming on reducing preventable child deaths from pneumonia, diarrhoea and newborn complications in Timor-Leste. The research sought to define behavioural and social change outcomes by identifying a) barriers that prevent communities from adopting healthy behaviours and best practices for timely and appropriate care seeking, and b) the positive motivations and triggers that contribute to an enabling environment and support communities to seek care. It therefore presents a strong evidence base to inform programme design and develop robust but nuanced communication for development strategies.

Methodology

The research was conducted in line with prevailing ethical principles to protect the rights and welfare of all participants. Permission to undertake the research was granted by the Ministry of Health of Timor-Leste and supported by the UNICEF Country Office in Dili.

Fieldsites were chosen by the Ministry of Health and UNICEF based on the ethnic and linguistic diversity they presented. Three districts were selected, and in each, three sub-districts were visited: in Baucau district, Vemasse, Venilale and Baucau (Baucau Hospital); in Ermera district, Railaco, Ermera Lama and Gleno; and in Oecusse district, Pante Makasar, Passabe and Oesilo.

Data collection was carried out over 18 days in October 2013 through in-depth interviews, semi-structured focus group discussions and technology surveys. In total, there were 177 participants across the nine sub-districts included in research activities.

Primary caregivers of newborns and children suffering from (or recently suffered from) pneumonia and diarrhoea were purposively selected for interviews and focus group discussions in order to capture their recent experiences of childbirth and/or child illness. Additional interviewees included traditional birth attendants, religious personnel and community health workers. Focus group discussions were also held with mothers, fathers, traditional birth attendants, community and political leaders, religious leaders, hospital and clinic staff, and key NGO and UNICEF representatives.

All interviews and focus group discussions were conducted by the English-speaking primary investigator with a locally recruited research assistant translating between English and Tetun or English and Baikeno. Each interview lasted for approximately 60 minutes and each focus group discussion for approximately 90 minutes. Audio recordings were made using a digital voice recorder and, along with field notes, served as the basis for transcriptions. Local research assistants collected technology survey data.

The primary investigator was responsible for all thematic analysis. Dominant themes were identified through the systematic review of interviews, focus group discussions and technology surveys. The occurrence and reoccurrence of salient concepts were labelled throughout and emerging trends were critically analysed according to the research objectives. Coding and analysis was done by hand for qualitative data and through

Excel statistical analysis for survey data. Computer-assisted qualitative data analysis software (ATLAS.ti) was used to analyse a sub-set of coded textual data to verify emergent themes. Initial findings were presented to key Ministry of Health and UNICEF staff at a roundtable workshop at the conclusion of data collection.

Report structure and outcomes

The research provides important new empirical data that contributes to understanding local barriers to newborn care and the treatment of childhood pneumonia and diarrhoea in Timor Leste. By exploring complex issues regarding child health, this report is designed to be of operational use to the Ministry of Health, UNICEF and their partners at local, national and international levels. The report presents a rapid review of the published literature and relevant policy and programmatic documents. It then outlines the demographic details of the primary caregivers interviewed and subsequently has six main sections: theories of causation, symptom recognition and prevention; care-seeking behaviours and practices; barriers to care seeking and treatment; solutions to barriers identified and drivers to care seeking; technology use for behaviour change and communication; and conclusion and recommendations. Prior to its completion, the Ministry of Health and UNICEF were given the opportunity to provide written and verbal feedback that was incorporated into the final report as appropriate.

The findings of this formative research should be used as a platform for an in-country workshop to develop communication for development strategy in 2014. In addition to the report, a complementary Powerpoint presentation has been designed that orientates results around the Social Ecological Model (SEM) in order to identify behavioural and organisational points to leverage communication activities.

A – Causation, symptom recognition and prevention

Pneumonia

Caregivers' knowledge of pneumonia symptoms was overwhelmingly concentrated on coughing and fever. This had implications for how caregivers understood the cause and recognised the condition of pneumonia. Frequently, the earliest sign of pneumonia was perceived as an individual symptom that was not dangerous until a subsequent symptom emerged, by which time the illness was likely to have progressed. This interpretation influenced care-seeking behaviour, and often led to delays. In Ermera and Baucau, caregivers suggested that pneumonia was caused by dust, heat and drinking un-boiled water. Other factors expressed included eating unclean vegetables, eating before washing hands, seasonal temperature changes and the diet of breastfeeding mothers. The attribution of pneumonia to dust and strong winds explains why most caregivers in Baucau and Ermera described an increase in the number of symptoms of pneumonia during the dry season. There was, however, little consensus over the timing and progression of the illness. In Oecusse, respondents did not ascribe pneumonia with the same casual factors as in the other two districts. Although dusty air quality and drinking un-boiled water were mentioned by a number of caregivers, the majority stated that children 'falling down' or being carried 'wrongly' by mothers or older siblings were the most common causes of pneumonia. Unlike in Baucau and Ermera where coughing was linked to pneumonia and connections were made with 'a wound in the lung', in Oecusse, a child's difficulty breathing was instead attributed to an external accident that caused the pain in their chest. Caregivers in all three districts, particularly those who had encountered health workers during the course of their child's pneumonia, suggested common forms of prevention associated with avoiding dust and dirt. Given the environment in which most families lived (homes with thatched roofs and an earth floor, often close to dusty unsurfaced roads) mothers did not know how it was possible to prevent their children from being exposed to dirt and dust. Health workers at Ermera Lama clinic also suggested that a common cause of childhood pneumonia in their area was the practice of a mother and newborn staying close to the fire immediately following birth. In such cases, pneumonia was thought to be caused by inhaling the smoke from the fire. Interestingly, this was not forwarded as a cause of pneumonia by caregivers.

Diarrhoea

Caregivers discussed a wide variety of symptoms they associated with diarrhoea including watery stool, high fever, trembling/shaking, eyes that moved around too fast, sunken eyes, too much saliva in the mouth, wounds inside the mouth, swollen stomach, loss of appetite, physical weakness, frequent crying, sleeplessness at night and sleeping too much during the day. The signs that indicated severe dehydration (wounds in the mouth,

sunken eyes) were only suggested by mothers of children who were hospitalised with diarrhoea at the time of interview. Across the districts, there were three commonly reported causes of diarrhoea: breastfeeding mothers eating food that was not suitable for children; children 'being naughty' and eating 'wrong' or unripe fruit; and not washing picked fruit before eating. Attribution of diarrhoea to crops that are 'young' or 'unripe' may explain why the majority of caregivers described the number of cases of diarrhoea increasing during the wet season. In contrast to the robust list of symptoms, methods of prevention were not widely known, and most mothers claimed to have 'no idea' how to prevent diarrhoea, often '*because it happens suddenly*'.

Caregivers were also questioned about household water sources, sanitation and hygiene practices. In Baucau, '*if there is water*', the most commonly cited sources were government pipes or, if the pipes were dry, wells. All participants in Baucau reported to boil their water before drinking. The most common type of sanitation in Baucau was a pit latrine and the most cited method of disposing of a child's faeces was to allow dogs or pigs to eat them. Hand washing with soap was most commonly reported to occur before eating, after going to the toilet and after working. In Ermera, the most common source of water was through the public pipes, and only one mother reported using a well. Boiling or straining water was common and no interviewee discussed drinking water directly from the pipe. There were two main sanitation systems in Ermera: open pit latrines covered by palm leaves; and cement toilet structures with a water collection tank and a large spoon for scooping water to 'flush' the toilet. As in Baucau, children's faeces were usually not cleared but left for dogs or pigs to eat. Hand washing was reported to happen before eating and after going to the toilet. If soap was not available, then washing detergent would often be used. In Oecusse, the most common source of water was the government pipes, although only half of the caregivers interviewed reported to boil water before drinking and no one discussed filtering methods.

Although pit latrines covered by palm leaves were common, many caregivers also discussed defecating in the open '*out by the garden*'. Again, children's faeces were left to be eaten by dogs or pigs. Hand washing was reported to occur most often in the morning, after work or before eating, but the use of soap was variable, '*sometimes we use soap, sometimes we forget*'.

Pregnancy and birth complications

In discussing pregnancy and birth related complication, the initial response from most mothers was '*I don't know what goes on in my neighbour's house*', highlighting the frequency of home births, but also the level of privacy that is maintained, despite close living quarters. When questioned further on their personal experiences of pregnancy and birth, women described complications they had experienced including: high blood pressure; swollen breasts; bleeding; children born with 'blue skin' who had difficulty breathing; improper positioning of the child for delivery; and difficulties with regards to placentas. Traditional birth attendants (TBAs) in Baucau confirmed that incorrect positioning of the baby in the womb and the placenta coming out prematurely or being retained after birth, were problems they frequently experienced in their work. TBAs in Oecusse also suggested that a woman's womb could be in the wrong position and this necessitated them using traditional medicines to correct its placement. A TBA interviewed in Ermera confirmed that common problems she encountered included 'children being born with breathing difficulties', 'closed cervixes' and breech births. Perceptions of risk associated with labour and childbirth were varied. The only complication that mothers' perceived to have a discernable prevention method was the position of the baby in the womb. In order to prevent breech births, several precautions or courses of action that the mother should take were listed: not riding motorcycles or horses; visiting an *a samat* (traditional masseuse); having a traditional birth attendant check and move the child into the correct position. In both Baucau and Ermera, the cause of pregnancy and birth complications was mainly attributed to the hard physical labour mothers continued to perform in the months leading up to delivery.

Local theories of causation

In Timor-Leste culturally bound illnesses and local theories of causation remain strong. Although attributed to specific conditions, symptoms sometimes overlapped with those that may have indicated pneumonia, diarrhoea or potential birth complications. In relation to local illnesses such as *vistidu*, *bungkolo maten*, *horok* and *rai kutun*, biomedical intervention was often thought to be inappropriate or unable to cure the condition. Instead, traditional healers or *matan dook* (a specific type of traditional healer capable of diagnosing spiritual sickness) were to be consulted. Health workers at Ermera Lama clinic described patients who attributed their child's pneumonia or diarrhoea to spiritual causes including *horok* or *rai kutun* and suggested that local theories of causation often prevented parents from seeking biomedical treatment in a timely manner.

B – Care-seeking behaviour and practices

Plant medicine and home remedies

Aimoruk Timor (Timor medicine) was traditional, plant-based medicine, and was described in all three districts. Leaves, bark and roots were the most common ingredients, although most participants were unable to catalogue the names of plants used. An exception was the use of the candlenut tree that was frequently specified by caregivers. Both the green leaves and nut (*kami*) were used, the latter due to its high oil content making it an important component of poultices to be massaged onto the skin. Common cooking ingredients such as garlic, ginger and pepper, and in Oecusse, pomegranate and guava were often added to medicinal mixtures. For women experiencing a long or difficult labour, or mothers who had recently given birth, Baucau traditional healers often prescribed massages with candlenut oil, or advised their clients to boil its leaves and roots in water and then either drink the warm water or bathe in it. *Aimoruk Timor* was also used to encourage the production of breast milk and to treat child illness, particularly breathing problems and to reduce fevers associated with pneumonia. For children experiencing diarrhoea, a mixture of water, salt and sugar would be given to children. Oral Rehydration Salts and its home-made version were often the frontline treatment for diarrhoea. In their focus group discussion, health workers in Ermera Lama confirmed that parents often treated diarrhoea at home with the homemade 'Oralite', particularly if clinic supplies were low, but remarked how dangerous this could be if diarrhoea symptoms remained or intensified. Whether or not plant medicine was used as the first line treatment for child illness was largely determined by close and easily accessible the nearest health facility was. If the facility was far, or health staff were unavailable, for example when clinics were closed on Saturday and Sunday, then children were most often treated with *aimoruk Timor*. If their condition was not severe, caregivers in Baucau were likely to wait from one to three days to see if the plant-based medicine worked before seeking additional assistance. In Ermera this waiting period was generally three days to a week. Several caregivers suggested that if they presented their child at the clinic with a fever, the nurses would chastise them for allowing the child to become so sick before seeking treatment. It was common, therefore, for caregivers to treat a child at home in an attempt to reduce their symptoms before taking them to the clinic, in order to avoid perceived criticism from health workers.

A samats, traditional birth attendants, healers and *matan dook*

Across the three districts, it was common for participants to distinguish between four different types of traditional healers: those who assisted women during their pregnancy, primarily through massage (*a samat*); those who assisted women during labour (traditional birth attendants); those who made medicines from local plants for curing illnesses or broken bones (healers); and those who determined and treated the spiritual causes of physical illness (*matan dook*).

A samats were most commonly utilised by pregnant women in Oecusse to perform the specific function of massaging the stomach prior to birth to ensure the baby is correctly positioned and can be easily delivered. Mothers would often list two or three *a samats* who lived in close proximity and who they would visit when necessary. While all TBAs described performing the role of an *a samat*, but not all *a samats* were TBAs.
The timing and frequency of visits to the *a samat* were highly variable. Most women described only starting to visit an *a samat* during the seventh month of pregnancy, although others were massaged every day from discovering they were pregnant until they delivered.

Traditional birth attendants have long been an important source of healthcare for pregnant women and during delivery, particularly in rural areas where the population has limited access to government health centres. Across Timor-Leste, TBAs are both male and female. National statistics on the ratio of male to female TBAs do not exist, however, for those enrolled in this study (n=10) 50% were male and 50% were female attendants.

Throughout Timor's recent history, there have been several interventions aimed at training TBAs, particularly in clean and safe deliveries. TBA's in Passabe, Oecusse, described having beneficial working relationship with the local clinic 'since Portuguese times'. Although this was seen to be positive in terms of collaborative service delivery, there remained times when biomedical and traditional practices clashed. For example, the TBAs knew that doctors vaccinated a child immediately after birth, but they felt this practice should be delayed until the mother's *na mutin* (white blood) had cleared. Several of the TBAs who participated in the focus group discussion were against family planning and many continued to advise new mothers to practice *tur ahi*, staying close to the fire with their newborn for several weeks after birth. Since Independence, training of Timorese traditional birth attendants has been actively opposed in favour of facility-based deliveries. The SISCa programme has provided

health education to TBAs, informing them about the advice they should give and the practices they should *not* follow, rather than providing training for skilled attendance. This policy towards TBAs presents an interesting tension in which the SISCa programme targets TBAs to provide information to mothers, thereby recognising the influential standing TBAs have in the community, yet actively discourages them from providing the care which led to that status. Not all TBAs involved in the research had received training and whether or not they referred women to health centres during difficult labours was highly varied across study sites. One claimed never to refer mothers to health facilities but to manage pregnancies and deliveries with a degree of autonomy. In contrast, others claimed only to assist when labouring women were unable to reach the hospital in time. Amongst TBAs who were prepared to refer their clients to the hospital, weakness or lack of strength to push were perceived as danger signs that would encourage their referral.

The availability of TBAs differed across districts and sub-districts. In Baucau and Ermera all the TBAs interviewed stressed that they assisted with births in the woman's home, but only after being requested to do so by the woman or her family. In Oecusse, the one occasion when women would visit a healer's home was for massage from an *a samat* during pregnancy. Childbirth would always happen in the woman's own home. In Oecusse, more so than in either of the other two districts, it was common for a labouring woman to be attended by her close relatives (mother, father, husband, aunt) rather than assisted by a TBA or health staff. It was also notable in Oecusse, particularly in the sub-district Passabe, that the TBAs had a close working relationship with the local clinic. In discussions with health workers, community and religious leaders, it was evident that the majority of women who had a facility-based delivery did so because their homes were close by and the facility was easily accessible. It was accepted, therefore, that women who used the services of TBAs did so because they lived in distant rural areas that were inaccessible by car or ambulance, and often in more mountainous regions.

Traditional healers were visited frequently in Baucau (by caregivers and for their children) to seek treatment for fever, coughing and diarrhoea. If caregivers had used *aimoruk Timor* or plant medicines as the frontline treatment, then traditional healers were most often the second source of care if a child's condition did not show signs of improvement. Again, this was also influenced by the distance between the caregiver's residence and the closest health facility. After giving home remedies, most caregivers stated that they would wait between one and five days before consulting a traditional healer. The healer would then use a combination of plant medicine and massage to treat the child. Ermera Railaco residents stated they only had traditional birth attendants in their sub-district, but no healers. Residents in other sub-districts of Ermera and throughout Oecusse, did not describe visiting traditional healers for childhood illness, although many did describe a friend or relative who had sought out traditional treatment, so it can be assumed that healers are present in all districts, even if they were not frequently accessed by caregivers in the study's sample.

Matan dook are a type of traditional healer in Timorese culture whose specific function is not to cure illness through the use of plant medicines, but to diagnose the spiritual causes of an illness. *Matan dook* were also said to be able to foretell the future regarding sickness or death that had not yet occurred. If a child's condition was deemed appropriate for intervention by a *matan dook*, they could be consulted before the child saw a doctor, to correct any lingering spiritual sickness thereby making the subsequent biomedical treatment more effective, or after visiting a doctor, if the biomedical treatment had not work.

Health facilities and the SISCa programme

Living in close proximity to a health facility that was easily accessible was a positive determinant for seeking professional care. The widespread coverage of SISCa programmes and their penetration at the community level has markedly increased rural populations' access to health services across Timor-Leste. In all three districts studied, the staff of the SiSCa programmes, who were sometimes referred to by the Indonesian term '*kader*'*kader*', were regarded as frontline primary healthcare providers, particularly for antenatal care and child vaccinations. SISCa programmes operate at the district, sub-district, village and hamlet levels ensuring that caregivers in rural areas who are unable to visit district or sub-districts health facilities, would be more likely to access SISCa services in their immediate locale. Typically, SISCa held sessions in government buildings or meeting areas chosen by the community to be in close proximity to the greatest number of potential participants. All mothers interviewed had received between two and four antenatal care check-ups during their most recent pregnancy through the SISCa programme and reported that all their children older than two months had received vaccinations, either through the SISCa programme or from a static health facility. The timing of vaccinations, however, was highly variable across the districts and sub-districts.

In relation to child illness, care-seeking behaviour in Baucau was, in general, characterised by the recognition of symptoms, followed by either treatment at a health facility, or treatment with plant medicine for between one and five days until the child's symptoms improved. If the symptoms persisted or progressed or additional symptoms developed, care would be sought from either a local healer or the nearest health facility. If symptoms were identified over a weekend and biomedicine was the preferred first line treatment, caregivers would wait until the clinic re-opened on Monday morning to present their child for treatment. In Ermera, however, caregivers and health workers both confirmed that attendance with a sick child was often motivated by health facility distributing the food supplement fortified corn soya blended powder, commonly referred to as 'corn powder' (*batar uut*). A community health worker in the area confirmed that corn powder was a powerful incentive and that some parents appeared to seek medical attention only if it was provided.

In discussing facility deliveries, caregivers confirmed their primary motivation to give birth at a health facility was their preference for skilled attendance in case 'something went wrong'. This was particularly evident for first time mothers. Others discussed attending a health facility when their home birth was prolonged or complicated.

Caregivers who first sought health advice and assistance from local religious leaders were frequently referred to health facilities. Their priest would either represent the caregiver, discussing their case directly with health workers, or would be likely to arrange transport to a facility by a church vehicle.

Pharmacy

Medicines prescribed by health facilities were provided free of charge at the point of service delivery. It was rare, therefore, that caregivers self-medicated or purchased drugs from public pharmacies. In Ermera district, no participant reported buying medicines, although a small number in Baucau and Oecusse district had purchased drugs. Caregivers would buy medicine if they thought the prescription provided by a doctor was ineffective. Medicines were purchased from either the local pharmacy or from a travelling Indonesian drug vendor, primarily selling generic medicines from Indonesia.

Home births, immediate post-partum care and newborn practices

Of the 27 mothers interviewed in the three districts, 15 (56%) had given birth at home and 12 (44%) had given birth in either a hospital or clinic setting with healthcare staff in attendance. Of those who gave birth at home, 11 had been assisted by family members. Yet, Timor-Leste is in a period of transition where the tradition of giving birth at home is being increasingly replaced by facility-based delivery, both elective and in emergency. This was particularly evident in relation to younger women. The average age of the mothers who had delivered their most recent child at home was 29 years, whilst the average age of mothers who had delivered their most recent child at a health facility was 24 years. Amongst the eight first time mothers interviewed, only one had delivered at home. The group of mothers who reported a recent facility delivery had an average of two children each, whilst the mothers who had delivered at home, had an average of four children each. This suggests that younger women are increasingly having facility-based births, and the trend is likely to continue as they have more children.

The mothers who had delivered at home found it difficult to describe in detail what happened immediately following birth, generally stating that their family had 'taken care' or was 'responsible for that', with little or no elaboration. Those who had delivered at a health facility explained that the baby was placed on the mother's chest immediately after birth and that breastfeeding was quickly initiated. No mothers described difficulties breastfeeding. A few first time mothers mentioned their confusion over '*why it took so long'* for their milk to come, but this did not deter them from exclusively breastfeeding their child. When questioned about the length of time they should exclusively breastfeed for, most mothers responded six months. After that, *sasoro* (porridge) would be introduced.

Mothers across all districts discussed the common Timorese custom *tur ahi*, literally 'sitting fire'. This practice necessitates both mother and newborn to be sequestered inside the home for a period of time, from several weeks to three months, with an open fire and often closed windows and doors, '*in order to make the room warm*'. Caregivers perceived the fire to be beneficial to mother and child for several reasons: to help the mother produce more breast milk; to heat the mother's breast prior to feeding; to prevent swollen breasts; to prevent future sickness in the baby; and to 'strengthen a mother's back' so that she would not have pregnancies close together (e.g. to help with birth spacing).

Decision-making and agency to act

The influence of family and relatives was an important factor in care-seeking behaviour in Timor-Leste. Seeking treatment, both local or biomedical, was most often a family decision, with fathers and mothers-in-law being frequently deferred to. Across all three districts, it was common that the attending parent of a hospitalised child was the father, whilst the mother remained at home to care for the rest of the family.

Agency to act was more restricted for pregnant women and those who had recently delivered, particularly if they lived in close proximity to their husband's family. When discussing the location of birth, health workers remarked on the inability of expectant women to follow their advice, given '*many many times*' to delivery at the health clinic, due to their family's preference for a home birth and discussed the fact that because husbands forbade their wives from using family planning methods, women were unable to control the number or timing of their pregnancies.

C – Barriers to care seeking and treatment

Barriers to care seeking and treatment uptake that were identified by caregivers and other respondents were analysed according to five key themes: financial barriers; access barriers; socio-cultural and religious barriers; knowledge and information barriers; and health facility deterrents.

Financial barriers

The most significant financial barrier enumerated by caregivers was the cost of transport to access a health facility. Despite the fact that services and medicines were provided free of charge, the financial barrier associated with accessing health facilities was problematic. Caregivers discussed modes of transport and the required out-of-pocket expense to be major considerations prior to care seeking, concerns echoed by health workers and community leaders.

Access barriers

Transfer by ambulance was free, but the limited number of vehicles was insufficient to cover their target areas effectively. In addition, many villages had restricted access, particularly those at high altitude where the paths were rocky and often impassable for vehicles, and this further prohibited the use of ambulances. Because of the limited coverage of ambulances, participants suggested that even in an emergency situation it might be better to travel to the hospital independently rather than wait for an ambulance.

Caregivers who could not afford transport, or who lived in remote rural areas where transport was unavailable, often had to walk long distances carrying their sick child. The most common length of time to walk from home to health centre ranged from two to four hours. Unable to leave other young children at home, mothers were frequently accompanied by the sick child's siblings, and this could add significant time to the journey. Walking was seen to be particularly problematic during the raining season, when road access was further restricted. In relation to child birth, a mother in Baucau noted that '*it was better to go to the health centre to giver birth*' but asked how women most in need of the services were meant to get there. The mother of a newborn in Ermera echoed this concern, stressing that accessing healthcare was often a matter of life and death for residents in her district. TBAs in Oecusse recounted that they had to walk '*from the morning to evening'* in order to reach labouring women who lived in remote mountainous areas. An additional burden raised by participants was the need for hospitalised children and labouring women to be accompanied by other family members. This could put an added strain on the logistics of accessing healthcare, as relatives were needed to support the household in the village, but also the patient in the hospital, both socially and economically.

Health facility deterrents

Health facility deterrents are reviewed as three interrelated areas: limited clinic working hours and lack of health staff; attitude of health professionals; and lack of medical equipment, drugs and facilities. While these issues may not prevent or preclude attendance at health facilities per se, they were detrimental to positive and timely care seeking and may have negatively affected the quality of service provided.

Limited clinic working hours and lack of health staff: Caregivers found the operational hours of health facilities to be restrictive, in terms of limited clinic hours, Monday to Friday, and the fact that health facilities were closed over weekends. A notable exception was the clinic in Passabe, where, although being closed at the weekends, clinic staff would still treat emergencies. According to the times caregivers reported, the average waiting time at clinics across all three districts was between two and three hours, if caregivers arrived at 8am or earlier. If they arrived later, it was harder to secure an appointment and the waiting time would likely be longer. Caregivers also emphasised that there was a lack of health workers and that staff at hospitals were often over worked and too busy to properly attend to their patients.

Attitude of health professionals: Caregivers in all three districts described the negative attitudes of hospital doctors and nurses and related that staff were frequently angry, shout and are rude to patients. This was particularly noticeable in Baucau. Caregivers also discussed their mistrust of hospital personnel and suggested that staff did not provide information or explain conditions or treatment.

Lack of medical equipment, drugs and facilities: Although medicines were supposed to be provided free of charge at hospitals and clinics in Timor-Leste, and the need to pay for drugs was not raised as a financial barrier to seeking care, there were many instances when hospital stock-outs required caregivers to self-fund medication. Mothers frequently described presenting at a health facility with their sick child, and being told to come back at a later date, usually the following week, to see if new drug supplies had arrived. Interestingly, participants did not articulate the need for onwards referral as a barrier to care-seeking, although it presumably required additional resources (both financial and non-financial). In some cases, however, health workers arranged for medicines to be purchased on behalf of the caregiver. Several mothers confirmed that the potential lack of medicine influenced their decision about whether or not to take children to the clinic when they were ill, and it also negatively affected caregivers' perception of health workers. In addition to limited and unreliable supplies of drugs, health workers described their need for additional equipment. Staff at Baucau hospital, for example, suggested they needed basic first aid equipment. Mothers in all three districts emphasised the lack of space and privacy at both clinics and hospitals. In their focus group discussion, representatives from Health Alliance International, Childfund and CARE highlighted the lack of privacy for labouring mothers as a significant issue, particularly for women who came to the health clinics from rural areas or those living in poverty.

Knowledge and information barriers

In relation to child illness, it was striking that whilst caregivers admitted having low levels of knowledge, particularly regarding prevention, mothers found it very difficult to articulate why their knowledge was lacking, what more they wanted or needed to know, and where knowledge about their child's health should come from. Although caregivers could easily recite the medicines that their children had previously been prescribed, they had rarely been given any health advice by a health professional at a clinic or hospital. Despite this, they did not often perceive their lack of health education to be a result of health workers neglecting to provide sufficient information, rather they appeared resigned to not knowing. Given the high levels of morbidity and mortality amongst the study's participants, it was surprising that caregivers displayed such a low demand for knowledge and information. This has implications regarding how health education and communication for development should be designed and targeted.

In contrast, expectant and recently delivered mothers described frequent interactions with SISCa and other NGO staff on topics including: childhood vaccinations; proper maternal nutrition; the importance of antenatal care and breastfeeding; the need to deliver at a health facility; and to keep their home environment clean.

Socio-cultural and gender barriers

Although caregivers did not highlight socio-cultural barriers to care-seeking, other participants (including health workers, religious and community leaders) identified three main issues: the persistence of cultural traditions; familial preferences for many children (often to the detriment of women's overall health status); and gendered time constraints.

Cultural traditions: There was a persistence of cultural traditions influencing health-seeking behaviour. In Baucau, for example, religious leaders described some people's preference for traditional practices as a consequence of their fear of modern medicine and the low level of education of some caregivers, and health workers appeared to accept that people continued to visit different traditional healers, including *matan dook*, because health centres were not easily accessible.

Family planning: All the participants in the study were Catholic and in terms of family planning, were influenced by the 'natural method' promoted by the Church. Although both religious leaders and health workers, including TBAs emphasised the need for family planning, it remains a sensitive issue in Timor-Leste and negative perceptions of Indonesian family planning programmes still linger. Some health workers associated the lack of responsible family planning with limited educational opportunities. Sometimes a woman would not recognise her pregnancy until the fifth, sixth or even seventh month because she was still breastfeeding her previous child. This delayed seeking antenatal care, not due to an unwillingness to attend or lack of access, particularly where SISCa programmes were operating, but because she was not cognisant of her condition.

Gender as a socio-cultural constraint: The impact of gender and gendered roles in Timorese society is a backdrop to many of the discourses on maternal and child health**.** Women have limited decision-making capacity, shoulder significant workloads (particularly in agricultural families) and lack educational and employment opportunities. The deleterious health effects on women are cumulative, with poor maternal nutrition and bodily stress directly contributing to the increased likelihood of obstetric complications and decreased newborn health outcomes**.** Gender inequities are compounded by the other financial and non-financial barriers identified, and these in turn are exacerbated by the over-stretched and under-resourced health system.

D – Solutions to barriers identified and drivers to care seeking

Having highlighted the barriers and deterrents faced by caregivers in seeking treatment for childhood pneumonia and diarrhoea and in relation to skilled birth attendance and newborn care, participants were also asked to share ideas and possible solutions to overcome the challenges identified. They were encouraged to consider what, from their perspective, would lead to the adoption of healthy behaviour and appropriate and timely care seeking for childhood illness.

Solutions to financial barriers

No caregiver was able to envision a way to ease the financial burdens they incurred from transportation costs to and from clinics. Free ambulances or 'clinic cars' were not suggested as a viable alternative to public transport as caregivers perceived their child's condition to be 'routine' or 'common' and not severe enough to warrant emergency medical assistance. Financial barriers were not discussed in terms of out-of-pocket expenditure for medicines, and no solution to overcome these surprise or additional costs was discussed.

Solutions to access barriers

The most frequently forwarded solution to access barriers was to increase the number of ambulances and clinic cars for emergency situations. Although participants recognised that in some rural settings vehicles were not always able to navigate the difficult terrain, still greater coverage of emergency transport was seen to be beneficial. An alternative solution to tackle access barriers was presented by Health Alliance International in relation to their mHealth programme *Liga Inan* (or 'Mobile Moms'). This pilot programme aims to improve maternal and child health outcomes by providing difficult to access communities with regular health information updates and reminders via SMS. To increase overall accessibility, several participants stressed the need to improve infrastructure, both general and health specific, and in terms of physical infrastructure and human capacity.

Solutions to health facility deterrents

Discussions about solutions to health facility deterrents emphasised the need for improved human resource for health, including increased capacity and capability, and better distribution of staff. The need for increased training, specialisations, better health worker to patient ratio and improved salaries were reoccurring themes articulated by health staff and community leaders. The need to improve current facilities was stressed, and in Baucau community leaders stated their local clinic had only one room for delivering mothers when at least four or five rooms were needed to accommodate the high demand. Similarly, a TBA in Vemasse emphasised that the local health centre was crowded and always busy, and suggested that a second health centre be built to increase positive health outcomes for mothers. A mother in Ermera, suggested that '*maternity home support'* should be given to mothers and basic supplies provided by the clinic, specifically a sarong for mothers to carry their

children properly, mats to sleep on, pails and buckets for drawing water, and basic medicines. Health workers in all districts cited their need for increased medical supplies (particularly oxygen and resuscitation equipment) and essential medicines to treat pneumonia and diarrhoea. Several TBAs recommended that partnerships should be fostered between traditional health providers who functioned at a community level and the local and district health facilities.

Solutions to knowledge and information barriers

Caregivers did not perceive their lack of knowledge or information on child health to be a barrier. Only in relation to the doctor's instructions to keep children away form 'dust and dirty things' in order to prevent sickness, did mothers in Oecusse, forward a concrete solution. In acknowledging that they could not readily change their immediate living environment, mothers suggested building a 'safe and clean' village playground. Because access to the SISCa programme and other NGO interventions was easier and more immediate than visiting a health facility, caregivers appeared to appreciate the information provided through these initiatives and implemented many of the recommended practices. Other channels of information that caregivers mentioned were the promotion of baby booklets that women received when pregnant and increasing the number of informative posters in clinic waiting areas and public places. Other respondents' suggestions for overcoming caregivers' limited knowledge most often involved using existing communication channels between community health staff, local religious leaders and key government services. Caregivers frequently recalled hearing health-related information during church services.

Solutions to socio-cultural and gender barriers

To counter the practice of *tur ahi* ('sitting fire') both TBAs and NGO staff proposed practical solutions that would satisfy the need for mothers and newborns to remain warm, but without the risk of smoke inhalation caused by the open fires. Alternatives suggested included mothers having hot drinks, bathing in hot water, and wrapping the baby in warm clothing. Promotion of such activities, paired with health messages that stressed *tur ahi* could be harmful, was the most cited method to reduce maternal and child pneumonia. To promote health behaviour and family planning, Health Alliance International had produced a range of films to be screened to community health workers and community members in villages and sub-villages across six districts in Timor-Leste with the aim that after a screening, further dialogue on health issues would be facilitated.

E – Technology use for behaviour change communication

Mapping the mobile landscape

In light of the potential benefits of mHealth technology for reaching rural or marginalised populations in Timor-Leste, the research team collected data related to specific mobile phone use and preferences as well as additional data related to television, radio and internet use.

Overview of current mobile health opportunities and constraints

Of the primary caregivers interviewed in Baucau (n=10) and in Ermera (n=9), four in both districts did not have a personal mobile phone although all had access to a phone through their husband or relatives. Of the primary caregivers interviewed in Oecusse (n=9), five did not have a personal mobile phone and two (did not have any access to a phone. In Passabe and Oesilo, Oecusse, caregivers described that it was difficult to keep their phones charged due to the limited supply of electricity. With regards to calling an ambulance in an emergency situation, most mothers felt they did not have the authority necessary to make such a call themselves but would defer to appropriate health workers or community leaders. None of the TBAs interviewed in Baucau had a mobile phone. If their services were required, clients or the relatives of clients would go to their home and request their services in person. Both of the TBAs interviewed in Ermera had a personal mobile phone, although this was not the method by which mothers would contact them. No father who participated in the focus group discussion in Pante Makasar (n=5) or TBA in the group discussion in Passabe (n=6) had a personal mobile phone but mothers suggested that owning a mobile phone was increasingly common for Oecusse residents and four of the six participants in their focus group owned a phone.

68.9% of technology survey respondents (n=62) had a personal mobile phone. The most common provider was Timor Telecom, the network used by 66.1% of all respondents with a mobile phone. Respondents also reported using Telemor and, in Oecusse, Telcomcel. In Baucau and Ermera, cellular reception was described to be generally good. In Oecusse, however, two respondents in Passabe had to climb to an elevated place to make or receive calls. The majority of respondents described their phones as being charged and ready to use everyday. Those who did not charge their phones everyday were more likely to have no credit at the time of the survey. USD 1 was the most commonly purchased credit denomination for topping up pay-as-you-go (pre-paid) phones. With regards to text messaging, only two respondents, both in Oecusse, stated that they did not send or receive text messages. Six other respondents across all three districts reported that they did not send text messages, but did receive text advertisements from their mobile provider.

Other technologies

Television and film: Television usage was common throughout all districts with the exception of Passabe, Oecusse due to poor electricity supply. 75.6% of participants (n=68) watched television on a weekly basis. Favourite programmes were reported to be the news (by 64.7% of respondents), movies and music shows. Radio-Televisão Timor-Leste (TVTL), a local Timor news channel, was the most frequently watched channel with the Indonesian language channels Indosiar and Indonesian TV being the second most watched channels. Time spent watching television ranged between ten minutes to 6 hours per day, with between 30 minutes and 2 hours being the most common viewing period. The majority of television watchers reported the evening, specifically 8 pm, to be the time of day when they would turn on their television.

Radio: Radio is widely perceived to be the most popular media for communication in Timor-Leste. 56.7% of the technology survey respondents (n=51) had their own radio or were able to listen to radios owned by family or friends. Radio Maubere and Radio Nacional de Timor-Leste (RTL) were most often reported to be respondents' favourite stations and news and music programmes listed as most popular. There was no generalisable timeframe in which respondents listened to the radio, with diverse listening hours including early in the morning (7am) and late in the evening (9pm). The time spent listening to the radio was less than that spent watching television, with most respondents suggesting they listened for an hour or less per day. In Passabe, Oecusse, where electricity shortages were common, only one respondent listened to the radio.

Internet: Although internet cafes are widely available in the capital city of Dili, they are virtually non-existent elsewhere in the country. Timorese who live outside the capital and who wish to access the internet, usually possess their own modems. Only four survey respondents (4.4%) had access to the internet: one in Baucau, two in Ermera, and one in Oecusse. The income levels of these individuals averaged USD 250 per month, far higher than the salaries of most participants. They reported to use the internet for checking Facebook, accessing email, doing job searches, looking for information, and in the case of one 20 year old mother, for her school assignments

Health-orientated programming

After Independence in 2002, broadcasting has been dominated by public radio and television outlets, although community radio stations have started to play an increasingly important role in the media landscape. Several NGOs broadcast health-related films at the community level, and sponsor short television spots, although they do not run mass media campaigns through the television.

F – Conclusion and recommendations

The formative research undertaken with caregivers, traditional birth attendants, community and religious leaders, and health professionals in Baucau, Ermera, and Oecusse Districts, has documented new empirical data on preventable child deaths from pneumonia, diarrhoea and newborn complications in Timor-Leste. The research identified barriers that prevented communities from adopting healthy behaviours and best practices for timely and appropriate care seeking, and the positive motivations and triggers that contribute to an enabling and supportive environment. The evidence generated through this research should be used to inform future programme design and communication strategies in support of the Ministry of Health in Timor-Leste to focus on under-served populations and end preventable child deaths, as in the pledge 'A Promise Renewed'. In conclusion, six interrelated areas of intervention are highlighted and associated recommendations made.

1) Core areas for communication interventions

- Improving caregivers' knowledge of illness symptoms, the progression of illnesses and timely care seeking, should be a priority in all three districts to counter the perception that some symptoms can be disregarded as routine. It is particularly important to highlight, for example, that drowsiness and lack of appetite are danger signs of childhood illness as many mothers only acknowledged crying as being problematic. Similarly, caregiver misconceptions regarding the causes of illness must be addressed.
- Communication interventions should focus on issues of disease prevention. The concept of prevention is poorly understood and this should be directly addressed in relation to both pneumonia and diarrhoea. This has implications for the key health messages health professionals communicate to caregivers and demonstrates a need to further invest in IPC and IMCI approaches.
- Key WASH messages should also focus on prevention, linking hand washing and sanitation procedures to disease prevention. Measures should be easy to incorporate into daily routines, such as boiling water prior to consumption (particularly in Oecusse) and removing children's faeces promptly. Reported practices of using washing detergent for bodily hygiene at home (when soap was not available) should also be reinforced.
- Caregivers who did not present their child for 'routine' or 'common' illnesses, were also dissuaded from attending health facilities due to travel times, associated costs and frequent stock-outs. In some sub-districts health workers promoted the use of homemade rehydration solutions as a viable alternative to ORS. Caregivers should be encouraged to give ORS or equivalent at the onset of diarrhoea and other illness episodes, and the correct measurements of salt/sugar/water should be stressed. This should be acceptable to and easily actionable for caregivers as it would complement the widespread custom of using plant-based medicines prepared at the household level.
- In continuing to promote exclusive breastfeeding and maternal and child nutrition, key messages should purposively address the concerns that mothers articulated about breast milk causing diarrhoea.
- Newborn danger signs should be emphasised, particularly the need for special care for low-birth weight and pre-term babies. Postnatal care should be strengthened and relevant messages included in the support materials for SISCa workers.
- The negative effects of post-natal seclusion and *tur ahi* should be made explicit and the practice slowly and gently modified to reduce the level of potential harm. In this regard, C4D could adopt a phased or incremental approach to behaviour change. For example, the strategy may first focus on the provision of ventilation in the room prior to the mother and baby emerging for vaccination.
- Negative attitudes expressed by healthcare workers have been reported by caregivers as contributing to their delay in and/or lack of treatment seeking at health facilities. C4D activities should aim to improve the attitudes of health professionals to ensure equitable treatment.
- It is important to engage all potential health providers (including *matan dook*) and target them through specific C4D strategies. For example, it should be better communicated both to TBAs and *a samat* that using massage to correct birth positioning may be particularly dangerous if done forcefully, and can lead to placental separation and ante-partum haemorrhage.

2) Opportunities for the adoption and promotion of appropriate healthy practices and actions

- Improving the quality and quantity of health education provided at health facilities is a central priority. Direct and indirect communication is required. Appropriate Social Behaviour Change Communication (SBCC) materials should be developed and introduced across the target areas. Importantly, health professionals should receive training on communication and counselling skills, and should be provided with necessary Information Education and Communication (IEC) aids to deliver effective health education.
- The potential of introducing maternal waiting homes should be considered. Although challenging due to lack of funding and already stretched human resources, maternity waiting homes may yield dividends in terms of providing increased access and serve as a valuable opportunity to promote health education. In addition, the provision of hospital robes for all labouring mothers should be considered. This may encourage mothers who previously were reticent to attend due to lack of appropriate clothing.

- The SISCa programme has achieved a high level of coverage and penetration and should be supported to provide targeted health education about pneumonia and diarrhoea and childhood illness.
- The church is a formidable channel for promoting health activities. Health facilities should maximise their collaboration in the Month of the Rosary and around other Catholic celebrations to mobilise community volunteers who go door-to-door in the months of May and October to convey relevant and timely health messages to the communities they serve.
- The opportunity to collaborate with local health providers including TBAs, *a samats* and healers (particularly *matan dook*) has not been well developed. Such health providers are trusted and respected members of the community whose influence and social agency should be better harnessed. With appropriate support they could distribute and reinforce key health messages and promote specific behaviours and practices. In Oecusse, TBAs worked collaboratively with health clinics. Both TBAs and nurse/midwives assisted in home deliveries, particularly in rural areas or where there were no separate facilities for labouring women at the local clinic. Further study is required to see if this leads to improved health outcomes, but it was perceived to be beneficial by the community, TBAs and health workers alike. As a way to improve the coverage of skilled assistance at birth, it could be piloted in other sub-districts.
- Similarly, local community support groups have reach and influence across communities and should be harnessed to promote appropriate health practices and actions.
- The viability of introducing conditional cash or commodities transfers for TBAs (for example if they referred mothers and engaged with programmes) has been shown to be an effective and efficient incentive in similar contexts, and could be considered in Timor-Leste.
- The literature reviewed suggested that information conveyed by school children to household members was generally held in high regard (Earnest 2004). School based health promotion activities should be further explored and utilised as a method to disseminate key health information to the community.
- Developing safe and clean community playgrounds may create environments that prevent children from playing in dusty streets, and be a valuable resource for mothers with several young children who are difficult to supervise adequately. The C4D positive deviance approach can be used to illustrate how caregivers may contribute to safer child play areas by sprinkling their courtyards with water to avoid dust.
- Optimal birth spacing and its link to improved maternal and child health should be routinely promoted, but should specifically target families experiencing unemployment, particularly those with out of work male household heads.

3) The feasibility for introducing mHealth

It is difficult to assess how receptive people would be to adopting a new and potentially disruptive technology and, in the abstract, it was challenging to determine the level of demand from caregivers or health professionals. With this caveat in mind, three points should be highlighted. First, given that caregivers did not call ambulance services and rarely called health workers, it may take substantial education to convince them that mobile health phones can be an effective health communication tool. In addition, because people were used to passively receiving promotional text messages, it may take time for caregivers to distinguish between marketing texts and messages that require them to enter into dialogue or take action. Whilst this should not deter programme implementation, it should be taken into consideration during the planning and design phase of pilots, whereby one-on-one recruitment and training of caregivers would be optimal. Secondly, community and religious leaders and health workers viewed themselves as important relay points in communication between a patient and a health facility. It is important that they be included in programme design and roll-out, to encourage community ownership and reduce tensions resulting from non-compliance with customary communication paths. Thirdly, advances in SMS should not negate the need for increased interpersonal communication between health professionals and patients. Increasing the responsiveness of doctors to patient needs during hospital/clinic consultations will only increase the value of SMS-based messages when face-to-face consultations are not possible due to distance.

In relation to the use of mHealth and other technologies by health personnel, it may be useful to consider the use of low-cost tablet computers for SISCa staff. There have been several promising health technology initiatives that have engaged community health workers by providing them with low-cost mobile devices to show

instructional videos and other visual media to primary caregivers. Some of the most promising mHealth applications that support community health workers not only deliver timely health education information, but also provide the capability to collate, track and monitor all routine Maternal Newborn and Child Health (MNCH) heath data, typically collected by a mobile workforce. Dristhi, the Smart Registry application system, has the potential to assist SISCa staff and other community health workers with compiling current registers, collecting data and the timely reporting of health events. CommCareHQ is another positive mHealth option that could potentially increase the capacity of healthworkers in their outreach activities. This technology utilises SMS for data collection with Java-enabled mobile phones (ideal for areas with limited wireless or 3G access), and automated text or voice message alerts reminding caregivers of appointments or providing timely health information triggered by upcoming events (such as pregnancy due dates).

Although the capacity of the telecom network to support mHealth interventions is currently limited, particularly in relation to poor network coverage, the expense of phone credit and sporadic electricity sources, the World Bank and other development partners are supporting telecommunications reform in Timor-Leste in collaboration with the government and private sector. Their efforts have resulted in licences being issued for multiple telecom operators and the introduction of regulations that promote much-needed competition in the market. A programme to support universal mobile and internet access in commercially less viable areas of the country is also being implemented. In light of this, it would be critical to agree with service providers on a basic or standard option package to support mHealth. Beyond collaboration with corporates, it would also be vital to actively engage with government IT departments to gain further understanding of any current or potential eHealth and mHealth strategies employed. Equally important is the use of unique identification (ID) and health data standards (ie. computer protocols that allow health information to be extracted from one system and transported to another) to enable interoperability between systems. Unique IDs (such as National IDs) are important in tracking the same person across multiple health departments and/or other government services.

Future mHealth programmes should draw on lessons learnt from Health Alliance International's pilot programme *Liga Inan* which is supported by Catalpa International's web-based platform. Several other initiatives have also set a good precedent. In 2012 the Alola Foundation, a Timorese NGO that aims to improve the lives of women and children, provided mobile phones to community volunteers in Ermera. The phones were pre-loaded with USD 15 credit and volunteers responsible for monitoring pregnant women were encouraged to call their local clinic when the woman started labour in preparation for facility delivery. Also Childfund have outlined a similar project in which health volunteers would be provided with phones to better monitor pregnant mothers. Despite these promising signs, however, Timor-Leste is not yet at a tipping point whereby mHealth would necessarily be quickly adopted. The introduction of mHealth interventions must be aligned to broader health system strengthening and be multi-phased, involving substantial awareness-raising activities at both community level and with health professionals.

4) Engagement of the private sector

Several potential partners from the private sector were identified to enhance child survival activities at both national and local levels. First, the dominant telecom company Timor Telecom who have majority market share and good network coverage across the country. Their partnership would be required for the effective roll-out of any mHealth intervention at scale and they could provide valuable promotional opportunities raising awareness of key health messages through positive marketing. Telemor and, in Oecusse, Telcomcel may also be relevant partners. As the preferred partner of Health Alliance International in the implementation of their pilot mHealth programme *Liga Inan*, Catalpa International should also be considered a potential private sector partner as they have experience in the specialised area of using technology as an agent for change.

Aside from exploring partnerships with the telcos to provide mHealth support, it may also be valuable to engage with them to share call detail records (CDR) of subscribers in the target areas (although there may be potential data protection and/or other regulatory issues to consider). This would facilitate a better understanding of mobility patterns (useful for modelling the spread of disease or disaster affected populations), social interaction (the identification of geographical distribution of social connections in order to develop demographic profiles by age and sex to identify behavioural patterns) and economic activities (estimating average household incomes of anonymous subscribers).

In terms of partnering with a national media organisation, Radio-Televisão Timor-Leste was the most frequently cited media outlet during the technology survey and was specifically mentioned as the best placement for health

programming by multiple caregivers. In order to reach the largest number of primary caregivers, health programming should be routinely aired at a set time and date so that planned (rather than opportunistic) viewing can be arranged. Given this, it would be important to develop a medium- to long-term plan with a broadcaster to strategise on when to air target messages. The connection of radio and television under one national outlet may also facilitate simultaneous or mutually supportive streams of communication to be aired through multiple channels.

5) Key advocacy issues

Representatives from the Ministry of Health, UNICEF country office and the NGOs Childfund, CARE and Health Alliance International were asked to provide their views on key advocacy issues through which to elevate the priority of and resources for reducing childhood morbidity and mortality due to pneumonia, diarrhoeal disease and newborn complications. Their responses were clustered around five main themes.

Policy and strategy: Stakeholders identified seven thematic areas that present key challenges to equitable healthcare for women and children in Timor-Leste: poor road conditions; child malnutrition; persistent cultural customs; poorly trained / poorly distributed workforce; low community awareness of health information; low socio-economic status of communities most in need of health services; lack of consistent and standardised policies. The need to match demand for healthcare with the reliable and realistic supply of services was emphasised. Stakeholders concluded that appropriate infrastructure must be put in place before expecting caregivers to adopt best practices. According to the Ministry of Health, plans commit them to equip all *sucos* with a health post staffed by doctors, nurses, midwives, technicians and with an ambulance. If and when this plan is realised, many of the access barriers cited in this research are likely to be addressed. The government must be supported to accelerate their efforts towards achieving this target and ensure that local community leaders are cognisant of the *suco* development plans.

Planning, management and coordination: UNICEF provides technical support to the Ministry of Health to assist with planning and development and raising community awareness through multiple interventions. Outside the Ministry of Health, however, there was little coordination or collaboration with other areas of government. It was recommended that the Ministry of Education, Ministry of Agriculture and Ministry of Transportation work together to better integrate rural development plans. Community-wide sanitation (CWS) remains a major challenge in Timor-Leste and engagement in related activities remains low. UNICEF and the Ministry of Health are the main institutions advocating the CWS agenda, and with only a small number of NGOs engaged in related activities, there is urgent need for improved planning, management and coordination across the sector. In addition, stakeholders commented that capacity within the Ministry of Health been hampered as many senior officials had been relocated during recent political reshuffles. This resulted in the loss of technical and operational experience and institutional memory. The need for continued capacity building at the Ministry of Health was emphasised.

Human resources: The lack of human resources for health in terms of trained health professionals and their distribution was highlighted. Stakeholders discussed the limited number of trained midwives as a primary contributor to poor outcomes for newborns. Changes to the structure of the Timor health system have resulted in decentralisation of resources, with increased investment in rural health posts. This was regarded by all stakeholders to be a positive development, but more properly staffed health posts were required to achieve adequate coverage. The shortage of Timorese midwives represents the largest gap in the country's health workforce, although there is also a striking shortfall in the number of qualified doctors, particularly those prepared to work in rural areas. In regards to training deficiencies among those healthcare workers who currently serve in sub-district and health post positions, poor interpersonal communication skills between doctor and patients were cited as a major concern. This was particularly troubling given that rural health workers (doctors, nurses, midwives) are the frontline providers and, at least in theory, are the primary agents for behaviour change. As a key source of health information, there needs to be sustained dialogue between health workers and the communities they serve, and stakeholders concluded that this was not the case in many districts.

Supply chain management: Major gaps exist in the distribution of medicines and result in significant and frequent stock-outs. *Service Autonomo de Medicamentos e Equipamentos de Saude* (SAMES) is the supply chain management system used across Timor-Leste and is seen to be largely effective. The root cause of clinic stock-

outs is thought to be failure by local health workers to appropriately manage their stock, anticipate shortages and request or re-order supplies in a timely fashion.

Political advocacy: Political commitment to address preventable child deaths in Timor-Leste is needed at all levels. Communities invest great political capital in their village chiefs and sub-chiefs, and in local religious leaders. As trusted officials with reach and influence across their communities, these figureheads must be consulted and actively involved in the design and implementation of health initiatives. Village chiefs in particular are seen to take great pride in their position, and the sustainability, impact and positive outcome of any intervention is dramatically increased through their support and advocacy. Stakeholders emphasised that amongst high-ranking political leaders in Timor-Leste there is recognition that the health system requires ongoing reform. Targets and strategies have been developed and positive momentum needs to continue for the government to increase budget allocations for future healthcare programming. In working collaboratively with the Ministry of Health to support their policies and interventions, agencies such as UNICEF have an important role to play in strengthening the health system in Timor-Leste.

Mother with newborn son, Oesilo, Oecusse Distict

Contents

Tables

Photographs

Acronyms

ANC	Antenatal Care
AusAID	Australian Agency for International Development
BCC	Behaviour Change and Communication
CDR	Call detail records
CHW	Community Health Worker
CWS	Community-Wide Sanitation
DHS	District Health Surveys
EAPRO	East Asia and Pacific Regional Office
GPS	Global Positioning System
HAI	Health Alliance International
ICT	Information and communications technology
ID	Identification
IEC	Information Education Communication
IMCI	Integrated Management of Childhood Illness
IPC	Interpersonal Communication
KAP	Knowledge Attitudes and Practices
LMIC	Low and Middle Income Country
MDG	Millennium Development Goals
MICS	Multiple Indicator Cluster Survey
MNCH	Maternal Newborn and Child Health
MoF	Ministry of Finance
MoH	Ministry of Health
MUAC	Mid-Upper Arm Circumference
NGO	Non-Governmental Organisation
ORS	Oral Rehydration Salt
PDA	Personal Digital Assistant
PSF	Promotor Saude Familia / Family Health Promoter
RTK	Radio Timor Kmanek
RTL	Radio Nacional de Timor-Leste
RTTL	Radio-Televisão Timor-Leste
SBBC	Social Behaviour Change Communication
SISCa	Sistema Integradu Saude Comunitaria / Community Health Integrated Service
SMS	Short Message Service
TBA	Traditional Birth Attendant
TLNSD	Timor-Leste National Statistics Directorate
TVTL	Televisão Timor-Leste
U5MR	Under 5 Mortality Rate
UNFPA	United Nations Population Fund
UNICEF	United Nations Children's Fund
UNMIT	United National Integrated Mission in Timor Leste
UNTAET	UN Transition Administration for East Timor
USAID	United States Agency for International Development
WASH	Water Hygiene and Sanitation
WHO	World Health Organisation

Glossary

***Aldeia*:** Sub-village or hamlet.

A samat: Traditional masseuse who pregnant women attend to massage their stomach so that children will be born in the correct position.

Aimoruk Timor: Traditional Timorese medicine.

Alin: Placenta, literally means brother or sister. *Alin* means something that comes after the baby is born.

Avong sidauk mai: When the placenta is not delivered after birth.

Baboton: Fontanelle.

Batar uut: Corn-powder food supplement distributed to families in poverty and/or those with children who are malnourished.

Be manas fakar: When a woman's water breaks before delivery.

Buan: Witch.

Bungkolo maten: When a person's body shakes violently, as during a seizure.

Fo'er mai: *Fo'er* (dirty) and *mai* (comes) refers to liquid that comes out before the baby comes, literally means 'dirty water comes'. Can also be phrased '*bee fo'er*' which means 'dirty water'.

Han sala: Eating the wrong food resulting in sickness.

Horok: Sickness caused by bad magic, taboo.

Horok boot: Bad magic that obstructs delivery in some way, preventing the child from progressing easily down the birth canal.

Horok mantolun: Bad magic that comes from the right and left side of a woman's body and obstructs delivery in some way, preventing the child from progressing easily down the birth canal.

Hotar: A statement made to a blood relative that results in their illness. Swearing to relatives and causing them to become sick.

Kader: Indonesian term referring to village health volunteers, equivalent of Timorese SISCa staff.

Kareta tula mate: Hearse or mortuary vehicle for transporting dead bodies.

Kanotak moras: Labour pain.

Knuk foun: Young mother with her first child.

Kurcaci: Ghost or spirit.

Matan dook: Traditional Timorese healer that can divine the cause of illness caused by social transgression or spiritual causes.

Na mutin: White blood. When a woman feels dizzy or cold and has a headache after giving birth. Generally attributed to lack of blood or low blood pressure after birth.

Partu tamun ho ahi: Staying close to the fire when giving birth.

Rai kutun: A living spirit that is bad. The name literally translates as 'Earth bug'. The spirit may cause sickness to children who pass too close to where the spirit lives.

Ran menus: Lack of blood.

Sarampu: Chicken pox/ Varicella zoster virus.

Sasoro: Porridge, commonly given to Timorese children, made from rice that is boiled for an extended period until it become soup-like in consistency.

***Suco*:** Village

Soru: Portuguese term for giving intravenous fluids.

Tara bandu: Small sticks (grass or leaves) bundled together that have been imbued with spiritual power by a *matan dook*. The bundles are hung in a place of importance, such as a fruit tree or near crops to make it taboo (*horok*) for any person to take the produce without permission.

Tur ahi: *Tur* (sitting) and *ahi* (fire). Refers to a cultural practice in Timor-Leste whereby mothers and their newborns stay in a closed room next to an open fire for several weeks after delivery. Local customs require the mother and child to stay warm, and heat from the fire is said to be beneficial. Doctors suggested this practice contributed to maternal and child pneumonia due to their inhaling the smoke.

Vistidu: Sickness affecting children that is characterised by the rapid onset of high fever, shaking or jerking in the arms and legs, eyes rolling back in the head, and potential loss of consciousness. This sickness is thought to have the power to kill children within hours or days.

Paddy field during the dry season, Pante Makasar, Oecusse District

Introduction

Background

Successful interventions have been undertaken to advance countries towards their Millennium Development Goal 4 (MDG 4) – reducing child mortality. Since the inauguration of MDG commitments in 1990, child mortality has reduced globally by two-thirds through the implementation of coordinated interventions and outreach services to impoverished and marginalised communities. Within this overall context, progress has been significant. Yet 6.6 million children under five died in 2012, mostly from preventable diseases (United Nations 2013a).

Reaching MDG 4 will require further sustainable and measurable progress targeting the poorest and most vulnerable regions, namely sub-Saharan Africa and Asia. Statistical analyses suggest that the risk of death before age five depends predominantly on location: global, regional and local (United Nations 2013a).

Improvements in child survival at the regional level are evident, with Eastern Asia and Northern Africa at the forefront. These are the only regions that have already successfully met their MDG 4 goals (United Nations 2013b; United Nations 2013a). Importantly, Latin America and the Caribbean, South East Asia and Western Asia have reduced their under-five mortality rate (U5MR) by more than 50% of recorded 1990 rates, while sub-Saharan Africa and South Asia have achieved reductions of 39% and 47%, respectively. South Asia has made the largest absolute reduction in preventable child deaths, halving its number of under five deaths since 1990 (United Nations 2013a). Despite this achievement, nearly one in every three global under-five deaths, occurs in this region (United Nations 2013a). Focusing on those regions where rates of child mortality remain high is, therefore, essential.

Of the 6.6 million child deaths that occurred in 2012, 17% were due to pneumonia and 9% to diarrhoea. Worldwide percentages of neonatal deaths have increased from 36% in 1990 to 43% in 2011. Data shows that a growing proportion of infant mortality occurs at or around the time of birth – a clear sign that child survival efforts must focus on the precarious first month of life (United Nations 2013a; Independent Expert Review Group 2013). Regionally, Latin America and the Caribbean, the Middle East and North Africa, South Asia, and East Asia and Pacific accounted for more than half of neonatal deaths in children under-five years of age in 2012 (United Nations 2013a). Despite these regional successes in meeting MDG 4, the number of preventable child deaths remains high worldwide, with the burden of mortality heavily concentrated in the poorest locations, particularly among newborns (Bhutta and Black 2013).

Pneumonia and diarrhoea remain two of the largest killers of children under five and, together with malaria, account for one third of child deaths worldwide (UN Inter-agency Group for Child Mortality Estimation 2013;UNICEF/WHO 2013). Simple, inexpensive treatments are available for each of these conditions, yet too few children receive appropriate and timely care, particularly in high burden countries and in the most deprived settings due to a range of interrelated factors. By promoting basic yet effective practices such as breastfeeding, hygiene, use of improved sanitation and safe drinking water, many deaths can be avoided. These low-cost, basic interventions focus on the efficient use of already existing institutions and require optimised communication and coordination between related stakeholders (Kalita 2006; Parlato et al. 2004).

Significant national and sub-national progress can be achieved using these proven interventions: when integrated strategies are implemented and backed by relevant research, adequate economic resources, and political will, children's lives are saved (Shefner-Rogers 2013). This is the focus of 'Committing to Child Survival: A Promise Renewed', the global movement to end preventable child deaths that emerged from the Child Survival Call to Action convened in June 2012 (UNICEF 2013b).

An important component of this movement is Communication for Development (C4D). C4D is a systematic, strategic and evidence-based approach to promote dialogue at local, national, regional and international levels in order to improve health indicators and encourage best practices. Its purpose is to implement timely, relevant and acceptable policies that drive positive social change for healthy behaviour. There are four core components to successful implementation of C4D: behaviour change communication (BCC); social change communication; social mobilisation; and advocacy. C4D strategy development is participatory, aiming to build capacity amongst relevant stakeholders and encourage community buy-in. C4D recognises that in order to be relevant and effective, health behaviour messages need to work on both an individual and collective, or societal, basis (Shefner-Rogers 2013).

Timor-Leste has signed the 'Promise Renewed' pledge that calls for a targeted approach to focus on under-served populations and the residual burden of preventable child deaths (UNICEF 2013b). Although Timor-Leste has reached its MGD 4 target to reduce child mortality, there continue to be wide intra-district disparities. This formative research provides the Ministry if Health, UNICEF and partners with a strong evidence based from which to develop robust but nuanced C4D strategies that will be implemented to further reduce the burden of pneumonia, diarrhoea and newborn complications.

Research brief and objectives

UNICEF East Asia and Pacific Regional Office (EAPRO) commissioned formative research to inform integrated programming on reducing preventable child deaths from pneumonia, diarrhoea and newborn complications in Timor-Leste. The research sought to define behavioural and social change outcomes by identifying: a) barriers that prevent communities from adopting healthy behaviours and best practices for timely and appropriate care-seeking; and b) the positive motivations and triggers that contribute to an enabling environment and support communities to seek care.

Most of the existing information from Timor-Leste was limited to quantitative data from the Timor-Leste National Statistics Directorate (TLNSD), Timor-Leste Demographic and Health Survey (DHS) and Multi Indicator Cluster Surveys (MICS) and lacked insights into access and participation issues of disadvantaged populations. Frequently, the thrust of communication campaigns was on awareness raising for mothers, without understanding the role of significant others and the socio-cultural norms that may hinder or facilitate an effective translation of knowledge into practice leading to the desired outcome (in this case, child survival).

This formative research provides insights on three key areas:

- Barriers that prevent the adoption of healthy practices and timely care-seeking;
- Positive drivers that influence healthcare-seeking behaviour for childhood pneumonia, diarrhoea and newborn complications;
- Decision making processes associated with childcare and treatment seeking for childhood illnesses.

It therefore presents an evidence base to inform programme design and communication strategies and will determine:

- Core areas to focus communication interventions using community dialogue processes and other communication channels identified;
- Opportunities to enable caregivers, communities and healthcare personnel to adopt and/or promote appropriate healthy practices and actions;
- The social media landscape and the feasibility for introducing mHealth;
- Potential engagement of private sector organisations, social network and the media in national and local interventions to enhance child survival activities at different levels;

- Key advocacy issues through which to elevate the priority of and resources for reducing childhood morbidity and mortality due to pneumonia, diarrhoeal disease and newborn complications.

Methodology

The research was conducted in line with prevailing ethical principles to protect the rights and welfare of all participants. Permission to undertake the research was granted by the Ministry of Health of Timor-Leste and supported by the UNICEF Country Office in Dili, Timor-Leste.

Research team

The research team was led by the primary investigator, Dr Ginger Johnson (GJ), a Senior Research Associate at Anthrologica. She was supported by three national consultants recruited by Anthrologica, who served as research assistants and translators and administered the technology questionnaire. Celestina Da Costa worked with GJ in Dili, Baucau, Ermera and Oecusse. Francisco Luis Zartini Zahar Fernandes worked in Dili, Baucau and Ermera. Salomao Messac worked in Oecusse only. Dr Juliet Bedford, the Director of Anthrologica, managed the project, contributed to each phase of the research and provided technical oversight.

Study sites

Timor-Leste has 13 districts that are sub-divided into *sub-districtos* (sub-districts), *sucos* (villages) and *aldeias* (hamlets). Specific field sites were agreed in collaboration with Ministry of Health in Timor-Leste and the UNICEF Country Office (see maps in Appendix 1). Fieldwork was conducted over 18 days in October 2013 in three districts: Baucau, Ermera and Oecusse (see schedule in Appendix 2). Three sub-districts were visited per district: in Baucau, Vemasse, Venilale and Baucau (Baucau Hospital); in Ermera, Railaco, Ermera Lama and Gleno; and in Oecusse, Pante Makasar, Passabe and Oesilo. These districts and sub-districts were chosen by the Ministry of Health and UNICEF based on the ethnic and linguistic diversity they presented.

Baucau District is in North-Central Timor-Leste, to the east of Dili. It covers 1,508 square kilometres with the Wetar Strait as its northern coastline. Baucau consists of six sub-districts (Baucau, Laga, Vemasse, Venilale, Quelicai and Baguia) and fifty-nine *sucos*. The capital city of Baucau district is also called Baucau. Ermera District is in West Timor-Leste and covers 771 square kilometres. Ermera has five sub-districts (Atsabe, Ermera, Hatolia, Letefoho and Railaco) and 50 *sucos*. Ermera is a landlocked district renowned for its coffee production. The capital city of Ermera is Gleno. Oecusse District is an enclave in Indonesia, covering 815 square kilometres with the Savu Sea as its northern coastline. Oecusse consists of four sub-districts (Nitibe, Oesilo, Pante Makasar and Passabe) and 18 *sucos*. The capital of Oecusse is Pante Makasar. In both Baucau and Ermera, Tetun was the lingua franca, although in Oecusse, the local language Baikeno was more commonly spoken in rural areas.

The Sistema Integrado de Saude Comunitaria (SISCa) or Community Health Integrated Service, operates across all 13 districts of Timor-Leste. Respondents in Baucau and Ermera often described SISCa staff as their primary source of health related information for antenatal care (ANC) and childhood immunisation. Oecusse residents referred less to their interaction with SISCa health services than the other two districts. SISCa is a government-operated programme established in 2007 that aims to create opportunities to reach local communities using local health volunteers for community-based health activities and mobile clinics. Its staff outnumber health workers from hospitals, health posts and community health centres combined (UNICEF 2012a; UNICEF 2012b; Mosquera et al. 2009; Berthiaume et al. 2011). Since 2011, SISCa has provided health services from over 600 health posts across Timor-Leste with support from the Australian Agency for International Development (AusAID), US Agency for International Development (USAID), the European Union, World Bank, World Health Organisation (WHO), UNFPA and UNICEF. SISCa posts serve

local communities of at least 1,000 persons and/or 100-300 families. Working towards the national 2020 health goals, the Ministry of Health aims to establish one SISCa health post for every 100 Timorese families. Community leaders play an important role in ensuring that local SISCa programmes are operational and well attended each month. Services are provided each month, generally, in a central meeting point that is convenient for the greatest numbers of residents in a village or sub-village. The monthly sessions revolve around a 'Six Table Assistance System': Table 1, population registration; Table 2, nutrition assistance; Table 3, maternal and child health; Table 4, personal hygiene and sanitation; Table 5, healthcare services; Table 6, health education. The Timor government credits SISCa with the country's decreasing maternal and child mortality rates and fertility rate through increasing the access rural populations have to basic health services (Soares 2011).

Participants and recruitment

In collaboration with the Ministry of Health, research participants were recruited from each target sub-district to present a wide range of views, experiences and access differentials. When the research team arrived at each sub-district, they visited the local hospital, clinics and primary health centres and were introduced to local health workers who helped to identify participants for in-depth interviews and focus group discussions. Table 1 presents the interlocutors who participated in the research.

Table 1 – In-depth interviews, focus group discussion participants and technology survey respondents

	Baucau District			Ermera District			Oecusse District		
		No. of activities	No. of participants		No. of activities	No. of participants		No. of activities	No. of participants
Interviews	Mothers	10	10	Mothers	8	8	Mothers	9	9
	Religious personnel	2	2	Fathers	1	1			
	TBAs	2	2	TBAs	2	2			
				CHWs	1	1			
Focus Group Discussions	Health professionals	1	9	Health professionals	1	4	Mothers	1	6
	Community & political leaders	2	18				Fathers	1	5
	Religious leaders	1	4				TBAs	1	6
Tech. survey	Primary caregiver		35	Primary caregiver		27	Primary caregiver		28
Total			80			43			54

Primary caregivers of newborns and children suffering from (or recently suffered from) pneumonia and diarrhoea were purposively selected for interviews and focus group discussions in order to capture their recent memories and experiences of childbirth and/or child sickness. In the context of all three districts, all primary caregivers interviewed were mothers with the exception of one father at Gleno Hospital, Ermera, who was accompanying his hospitalised daughter. The technology survey participants were independently identified by the research assistants.

In Baucau District, the Ministry of Health assisted the research team to organise 14 in-depth interviews, ten with primary caregivers. Two interviews were held with traditional birth attendants: a female attendant in Vemasse and a male attendant in Venilale. Two interviews were also held with religious personnel: a priest in Venilale, and a nun working in central Baucau. Four focus group discussions were conducted: two with community and political leaders (influential community members in Vemasse n=12; and community and political leaders in Venilale n=6); religious leaders in Vemasse (n=4) and hospital staff at Bacau Hospital (n=9). Thirty-five technology surveys were completed with primary caregivers of children under five.

In Ermera, the Ministry of Health assisted the research team to organise 12 in-depth interviews, nine with primary caregivers (mothers n=8, fathers n=1). Two traditional birth attendants were interviewed (one in Railaco and one in Gleno) and a community health worker was interviewed in Railaco. One focus group discussion was conducted with health staff at Ermera Lama clinic (n=4). Twenty-seven technology surveys were completed with primary caregivers of children under five.

In Oecusse District, the Ministry of Health assisted the research team in organising nine in-depth interviews with mothers. Three focus group discussions were conducted: with mothers in Pante Makasar (n=6); fathers in Pante Makasar (n=5); and traditional birth attendants in Passabe (n=6). Twenty-eight technology surveys were completed with primary caregivers of children under five.

In total, the study included 177 participants: 35 people were interviewed, 52 contributed to focus group discussions and 90 completed the technology survey.

All participants across the three districts were given hand-washing soap and toothpaste to thank them for their time and contributions.

Data collection

Based upon a rapid review of published literature and programme documentation at the start of the research, GJ and JB devised a series of methodological tools including a topic guide that highlighted key issues and was the basis for the design of the semi-structured interview frameworks, focus group discussion frameworks and technology questionnaire. The tools included a broad spectrum of research questions and probes focusing on pneumonia, diarrhoea and newborn complications (see Appendix 3). UNICEF EAPRO, the Country Office and Ministry of Health had oversight of the tools prior to their implementation. Ethical clearance and permission to conduct the research was provided by the Ministry of Health Timor-Leste.

Specific questions and probes were reviewed and refined during the research period in light of themes arising. Although the direction of each interview was determined by the interviewee and largely focused on issues they self-prioritised (rather than on what the research team may have presupposed to be important), the key topics were addressed in each interview and therefore allowed generalisation of themes across participants and districts. The research was deliberately designed to facilitate inputs from multiple stakeholders in a step-wise manner, so that issues raised by one group of interlocutors could be discussed with other groups of interlocutors to help the collation of in-depth material and the rigour of its validation and triangulation.

All interviews and focus group discussions were conducted by the English-speaking primary investigator with a research assistant translating between English and Tetun or English and Baikeno. Each interview lasted for approximately 60 minutes and each focus group discussion for approximately 90 minutes. Audio recordings were made using a digital voice recorder and, along with field notes, served as the basis for transcriptions. Interviews were conducted at the home of the primary carer (with the exception of 6 mothers and one father who were attending hospitalised children, and one mother travelling to the clinic to receive a food supplement) and with as much privacy as possible. The technology survey, administered

to a different selection of participants than those enrolled in qualitative research, was conducted in the participants' home or in community spaces, clinics, and hospitals.

At the start of each interview, focus group or technology survey it was made clear to all potential participants that their involvement was optional and voluntary and would not affect any future referral or medical service required or received by themselves or their children. The study's consent was presented, explained in detail and read aloud for illiterate participants (see Appendix 4). Informed consent was given by signature of all those participating. At the conclusion of the research, all consent forms have been retained by Anthrologica.

Two additional roundtable discussions were facilitated in Dili, the first with UNICEF and Ministry of Health staff (n=5) the second with representatives from several Non-Governmental Organisations (NGOs) working in the sector: CARE, Health Alliance International (HAI) and Childfund (n=3) These discussions also addressed a set of policy-related child health questions devised by UNICEF EAPRO (see Appendix 5).

Data analysis

At the conclusion of each day of data collection, the primary investigator and research assistants would transcribe their notes and compile data for review and verification. Audio recordings of all interviews and discussions were transcribed into Microsoft Word by a research assistant and primary investigator and cross-reviewed for accuracy. Excel files inputting technology survey data were created daily by research assistants who then checked the spreadsheets against the original paper surveys. Preliminary analysis of qualitative and quantitative data was conducted throughout the data collection process. The primary investigator presented initial findings to UNICEF and Ministry of Health representatives at a round table workshop at the conclusion of data collection.

The primary investigator was responsible for all thematic analysis. Dominant themes were identified through the systematic review of interviews, focus group discussions and technology surveys. The occurrence and reoccurrence of salient concepts were labelled throughout and emerging trends were critically analysed according to the research objectives (Guest et al. 2012; Bryman 2008; Ritchie and Lewis 2008). Coding and analysis was done by hand for qualitative data and through Excel statistical analysis for survey data. Computer-assisted qualitative data analysis software (ATLAS.ti) was used to analyse a sub-set of coded textual data to verify emergent themes.[1]

Methodological limitations

Each study site presented operational challenges. Accessing rural areas of each sub-district required significant travel time due to harsh road conditions. The limited time and resources available for the research were reflected in the number of interviews or group discussions that could feasibly be completed during thirteen days of data collection. Team members sought to minimise the impact of these constraints by employing a pragmatic methodology aimed at utilising resources efficiently in the targeted districts.

Risks associated with miscommunication or mistranslation were mitigated by a member of the research team (who did not participate in interviews or focus group discussions) transcribing the interviews from the original audio files. These were then reviewed by the primary investigator. Sections of narrative were back-translated to confirm or clarify participant statements. Transcripts were cross-referenced with the research team's notes and any remaining areas of inconsistency highlighted for further clarification via a third review of the original audio file.

[1] ATLAS.ti (Scientific Software Development) is a qualitative analysis package – originally developed to support grounded theory – distributed in the United States by SCOLARI, Sage Publications.

One interview with a traditional birth attendant (TBA) in Vemasse, Bacau, required double translation between English, Tetun and Waimua. The research assistant (CD) translated between English and Tetun, as for other interviews, and the TBA's son translated between Tetun and Waimua. This increased the time required for translation and necessitated the number and complexity of questions asked to be reduced, but it did not affect the quality of the translation or data gathered.

It is possible that interviewees expressed answers they perceived to be appropriate or socially desirable, although due to the methodology employed throughout the research process, it is thought any potential bias was minimal. Observational data compiled during interviews in mothers' homes also served as a method of verification for information (eg. the existence of hand-washing stations and soaps, diaper disposal methods, etc.) Additionally, interview and discussion frameworks allowed similar questions to be asked in multiple ways in order to triangulate responses across relevant stakeholders.

Given the small sample size of the study, results cannot be extrapolated to a wider country context, although the saturation of findings in all districts indicates this data is likely applicable to mothers living in similar rural locations throughout Timor-Leste. The findings were broadly corroborated by the literature reviewed.

Report structure and outputs

This research confirms previous findings and provides important new empirical data that contributes to understanding local barriers to newborn care and the treatment of childhood pneumonia and diarrhoea in Timor-Leste. By exploring complex issues regarding child health, this report is designed to be of operational use to UNICEF, the Ministry of Health and their partners at local, national and international levels.

The report presents a rapid review of the published literature and relevant policy and programmatic documents. It then outlines the demographic details of the primary caregivers interviewed and subsequently has six main sections: theories of causation, symptom recognition and prevention; care-seeking behaviours and practices; barriers to care seeking and treatment; solutions to barriers identified and drivers to care seeking; technology use for behaviour change and communication; and conclusion and recommendations.

Prior to its completion, UNICEF and key stakeholders were given the opportunity to provide written and verbal feedback that was incorporated into the final report as appropriate.

The findings of this formative research should be used as a platform for the in-country development of C4D strategies in 2014. In addition to the report, a complementary Powerpoint presentation has been designed that orientates results around the Social Ecological Model in order to identify behavioural and organisational points to leverage C4D activities (see Appendix 6).

Mother and son, Passabe, Oecusse District

Literature review

Historical context

Timor-Leste was a Portuguese colony from the sixteenth century until the mid-1970s, when the Portuguese government relinquished its territories and the Indonesian state forcibly annexed the eastern half of the island (Nevins 2003). Australia was the only nation officially to recognise Indonesian authority over Timor-Leste. Under Indonesian rule (1975-1999), the health of the Timorese population suffered through widespread human rights violations and the maternal mortality rate rose to be one of the highest in the world (Traub 2000). The poverty rate in Timor grew to double that of Indonesia and independence movements were swiftly contained, isolating Timor from the rest of the region.

Several massacres in Timor during the latter half of the 1990s received international publicity, and in the spring of 1999 the then UN Secretary-General, Kofi Annan, asked Indonesia's president to disarm the militias, hold a referendum for Timorese Independence and permit foreign troops to supervise the voting process. Jakarta first refused (the UN sent 300 unarmed police officers to Timor-Leste in response) but then under strenuous diplomatic efforts by Annan and pressure from the international community, President Habibie requested the United Nations for assistance to restore peace and security. Shortly after the Australian Foreign Minister informed the Secretary General that Australia would be willing to accept the leadership of a multinational force in East Timor. A referendum was held in autumn 1999 and the population voted overwhelmingly against continued Indonesian rule (Povey and Mercer 2002). As the Indonesian militants withdrew, however, they systematically moved through the country destroying villages and towns. Over a two and half week period, 'almost every shred of personal wealth in East Timor was stolen or destroyed', and until the mass graves are excavated, it remains unknown how many Timorese lost their lives (Traub 2000).

The UN commenced peacekeeping operations in 2000. The country's infrastructure had been destroyed and institutional and personnel capacities decimated. Original plans to support local leadership to strengthen the legal, banking and political systems had to be modified, and in effect, the UN had to start re-building the country (Traub 2000). This complex nation building exercise was overseen by UNTAET (the UN Transitional Administration for East Timor) but led to a period of political struggle in which Timorese perceived UNTAET to be paternalistic and actually impeding progress to Independence. Timor-Leste became a sovereign state in May 2002. It was against this backdrop that the healthcare system was reconstructed.

Historically, Timorese relied on traditional care practices including herbal medicines and local spiritual healing (Povey and Mercer 2002). The Portuguese did not invest in the health system and during the Indonesian period, the weak infrastructure that had existed was largely destroyed. In 2000, UNTAET established the Division of Health Services (DHS), staffed by both Timorese and international health professionals. They attempted to correct for inequitable healthcare distribution across Timor, yet on-going political instability and economic insecurity curtailed efforts to develop a strong health system (*ibid*).

It has proved challenging to effectively communicate health information and increase demand for services due to the diversity of languages and ethnicities, and socio-political and economic determinants, all coloured by the emerging nationalism. Rebuilding an equitable health system has been shown, however, to be a stabilising factor in post-conflict zones (Kruk et al. 2010), and particular focus on reducing maternal and child mortality and morbidity can exert a positive influence on a country and population in transition.

The economy of Timor-Leste is dominated by the oil and gas sector (Australian Government 2013) and although the government has pledged to use oil wealth to develop the country's infrastructure, little has been allocated for rural development, and many villages continue to rely on subsistence agriculture (Schonhardt 2012). The country's Strategic Development Plan (SDP) has set a development goal of a middle income and diversified economy by 2030 (Australian Government 2013).

Socio-economic status, fertility and infant mortality

Timor-Leste has the third highest fertility rate in the world, and is currently 'enjoying a baby boom' (UNFPA 2009). The burden of disease is highest amongst children, however, with acute respiratory infections, febrile illnesses and diarrhoea remaining the most common causes of illness, hospital admissions and death amongst children (Deen et al. 2013; Bucens et al. 2013). The under-five mortality rate was reported to be 64/1,000 in 2010 with stark cross-district disparities: 42/1,000 in Baucau; 102/1,000 in Ermera and 92/1,000 in Oecusse (NSD/MoF/ICF 2010). The vast majority of births occur at home rather than at a health facility, and the rate of skilled attendance at birth is low (Mosquera et al. 2009; Dawson et al. 2011).

The urban-rural divide is a significant determinant of child vulnerability with a close correlation between the poorest quintile and rural residence (NSD/MoF/ICF 2010). Children in rural areas were more likely to have poorer nutritional status, less likely to be immunised, and less likely to be treated at a health facility when ill (Mizumoto et al. 2013; World Bank 2006). These indicators have been linked to a mother's education level. Communities in poorer areas tend to report fewer illness episodes in their children, which is consistent with findings that those who are less educated and have a lower socio-economic status are less likely to recognise and report symptoms (Rannan-Eliya et al. 2012).

Gender roles and care-seeking behaviour

Although some ethno-linguistic groups, such as the Bunka and Tetun-Terik speaking communities, are traditionally matrilineal, Timor-Leste is considered a patriarchal society with men dominating leadership and decision-making. Women's utilisation of healthcare remains significantly lower than men's, while male health professionals dominate the health workforce.

Again, education levels have been shown to be relevant in determining care-seeking behaviour and accessing health services. Girls receive an average of 1.5 years less schooling than boys (Myrttinen 2010), and whilst 88% of women with more than secondary level education gave birth with a skilled attendant, only 14% of women with no education had a skilled delivery (Asante et al. 2011). It was also reported that high levels of distrust about reproductive healthcare perpetuate, due a history of coerced sterilisation in the pre-Independence era amongst Timorese women who sought family planning advice (Asante et al. 2011).

Women are commonly considered the property of their husbands, and this sense of 'ownership' is reinforced by the paying of a 'bride price' (Ministry of Health 2004). A report by the Ministry of Health concluded, 'Many Timorese do not yet fully appreciate women's rights or embrace gender equality' (Ministry of Health 2004) and this was a major factor in the comparatively high rate of domestic violence. According to the Timor-Leste Demographic Health Survey (2009-2010), despite social taboos preventing discussion of domestic violence, 86% of women reported their belief that a husband is justified in beating his wife, with the most accepted reason being child neglect (76%). Approximately one-third of Timorese women were found to have experienced some form of physical violence in the previous twelve months, and 4% experienced physical violence during pregnancy (NSD/MoF/ICF 2010). The survey highlighted that whilst participants claimed health decisions were most likely made jointly between husband and wife, 72% of women believed that leaving the house without telling their husband (for example, to seek healthcare) was a justifiable reason for domestic violence. Mattson (2011) found that gender roles dictated particular responsibilities in relation to health practices, with decisions about sanitation (such as where and how to build latrines) being made primarily by male household heads, and responsibilities for hygiene practices (such as encouraging children to wash their hands before eating) being the domain of females.

Several studies suggest that the traditional role of women precluded independent decision-making and limited women in their social capabilities. Other family members, particularly a child's paternal grandparents, were found frequently to be involved in healthcare-seeking decisions and it was suggested that counselling mothers about particular health practices may be ineffective should her mother-in-law advocate another method (Mosquera et al. 2009).

Seeking professional care was closely associated with finding a cure, and the concept of prevention was limited (Zwi et al. 2009; Van Schoor 2003). Labour was conceived to be a normal non-medical event (Wild 2009) with widespread preference for home birth (USAID/Ministry of Health 2007) and in privacy (Zwi et al. 2009). Common discourses about normal deliveries at home were found to influence care-seeking practices, with some women admitting they did not take vitamin and iron supplements prescribed due to fears their baby would grow too big for a normal home delivery (Van Schoor 2003).

Sharing information related to child illness and the willingness to impart advice to other mothers appeared to be closely related to the socio-economic status. For example, poorer women in Ermera district were afraid of being perceived as proud or 'acting like a rich person' if they tried to share new information with anybody (USAID/Ministry of Health 2007). In contrast, information conveyed by school children to other household members was generally perceived to be modern, reliable and believable (Earnest 2004).

Cultural practices

Cultural practices and beliefs were highlighted as important components of health and healthcare in Timor-Leste. Studies concluded that biomedicine was generally praised for its efficacy and speed in curing sickness, whereas traditional medicine was claimed to be initially effective, but to result in reoccurring conditions (Zwi et al. 2009; World Bank 2006). Biomedicine and traditional practices were often used simultaneously or in rapid succession. Traditional providers would negotiate a ritual fee (*kasu*) as compensation and reassurance that the cured person would not fall ill again, but if treatment was not quickly effective, the community often suspected customary causes or social transgressions (Wild 2009; Zwi et al. 2009). In such cases, neither traditional medicine nor biomedicine would be effective until the cause had been resolved. Evidence suggests that this often resulted in treatment interruptions for childhood illness.

A practice that was emphasised in much of the literature was *tur ahi* (sitting fire), in which the mother and newborn entered a protective period of seclusion in the home and remained in close proximity to an open fire. Local customs required the mother and child to stay warm, and heat from the fire was said to be essential to 'close the pelvis', prevent illness, keep the mother from 'getting fat' and to remove 'dead blood', which could otherwise cause fever and infection (Van Schoor 2003; McWilliam 1994). The reported length of time the mother and newborn stayed inside varied from forty days (Wild 2009) to several weeks (MAMA 2013), or until the baby began to regularly feed (Van Schoor 2003). Unfortunately, the fires emit substantial pollutants, putting those exposed at higher risk of respiratory illness (Arcenas et al. 2012). In Timor-Leste, around half of the population cook with solid fuel, the majority without a chimney or ventilation and as the most exposed, women and children were found to be the most susceptible to increased rates of respiratory disease (NSD/MoF/ICF 2010).

Breastfeeding

Breastfeeding misconceptions were widely reported in the literature. In Ermera, women reported their strongly held belief that breast milk does not come for one to three days after giving birth, or only comes when the ancestors are pleased with the baby's name (USAID/Ministry of Health 2007). Colostrum was often discarded as dirty (a sentiment emphasised by older women), with mothers preferring to give 'white milk' to their babies. Senearath et al. (2006) found that 46.1% of children were breastfed within one hour of birth, 30.7% of children under six months were exclusively breastfed and that infants born at health facilities were less likely to be exclusively breastfed. The Demographic Health Survey (2009-2010) indicated more positive data, however, reporting that 82% of children were breastfed within one hour of birth, and 52% of children under six months were exclusively breastfed (NSD/MoF/ICF 2010).

A health sector review by the World Bank found that bottle feeding doubled the risk of children contracting diarrhoea and that the use of bottle feeding increased with higher levels of maternal education and wealth index as well as a lower maternal age (World Bank 2006). Almost half of the children under two months old

enrolled in the 2006 World Bank study were given milk and other foodstuffs in addition to breast milk, and by four to five months old, less than one quarter were exclusively breastfed with the prevalence of diarrhoea increasing sharply as a result (*ibid*.) Mothers also suggested that breast milk could be the cause of illness, and breastfeeding should therefore cease when a child becomes ill. Other studies concluded that exclusive breastfeeding was perceived to give insufficient sustenance to an infant at three to four months (USAID/Ministry of Health 2007) and that diarrhoea associated with teething was considered normal by many Timorese mothers (Zwi et al. 2009). In the treatment of diarrhoea, only 10% of children were given more than usual to drink (NSD/MoF/ICF 2010).

Water hygiene and sanitation

Studies also explored the link between hand washing and improved sanitation practices with disease control. The Knowledge, Attitudes and Practice (KAP) survey on Water Hygiene and Sanitation (WASH) undertaken in Timor-Leste by UNICEF in 2011 concluded that although 91.5% of households reported hand washing to prevent disease, there was limited understanding of hygiene associated with faeces and defecation (Mattson 2011). Only 17.4% of households identified poor hygiene or contact with faeces as a cause of diarrhoea, and 5.5% identified washing hands with soap and water as a way to guard against it. A Ministry of Health study in Ermera and Bobonaro districts noted that young children defecated next to the house with the faecal matter left for the dogs to eat. In the evening, a child may defecate on the floor inside the house, and this would be cleaned the following morning (USAID/Ministry of Health 2007). Mothers showed little concern for quickly discarding faecal matter. A minority of mothers was found to dispose of their child's faeces safely (NSD/MoF/ICF 2010) and less than 5% of adults reported washing their hands after defecation or cleaning their child (Mattson 2011).

In previous UNICEF studies, Baucau, Ermera and Oecusse districts reported only a small proportion of the population used improved sanitation facilities, with all areas in Oecusse below the MDG target levels (UNICEF 2012a; UNICEF 2012b; UNICEF 2012c). The UNICEF KAP survey found that 70.7% of the population were without access to improved sanitation and 54.5% did not have access to improved water sources. The two districts with the highest reported incidence of diarrhoea (Manatutu and Viqueque) also had the highest reliance on surface water. Amongst households who did not treat or boil their drinking and cooking water, 44.2% reported that they did not know how to, and 38.5% did not think it was necessary (Mattson 2011). According to Demographic Health Survey (2009-2010) 18% of the population in Timor-Leste had access to piped water although in Ermera the 'pipes' were made of open bamboo and were tapped illegally by other communities (NSD/MoF/ICF 2010). Nationally 66% of Timorese access government water; 57% in rural areas. One in three Timorese still practise open defecation and a total of 61% do not have access to improved sanitation (WHO/UNICEF 2013). In general, however, treatment indicators for diarrhoea demonstrated good recognition of danger signs associated with diarrhoea (Zwi et al. 2009) and rates of Oral Rehydration Salts (ORS) use were considerably higher in Timor-Leste than other southeast Asian countries (World Bank 2006). The Demographic Health Survey (2009-2010) concluded that 71% of Timorese children with diarrhoea were treated with ORS (NSD/MoF/ICF 2010).

Barriers to care seeking

Studies addressing barriers to healthcare commonly cited limited infrastructure, poor service quality, dismissive attitudes of healthcare providers and geographic distance as the major obstacles (Deen et al. 2013; Martins et al. 2012). The Demographic Health Survey (2009-2010) listed the major challenges faced by Timorese women in accessing healthcare for themselves and their children to include: concerns over the availability of medicines; the limited availability of (female) providers; distance to point of care and availability of transport; lack of money; lack of permission from family or husband; and not wanting to seek care alone (NSD/MoF/ICF 2010).

In Timor-Leste, the government has pledged access to free comprehensive maternity care, including quality antenatal and postpartum care and clean and safe delivery for all women (Snell et al. 2005). According to

the Constitution, '*The State shall promote the establishment of a national health service that is universal and general. The national health service shall be free of charge in accordance with the possibilities of the State and in conformity with the law*' (Government of Timor-Leste 2014). Although out-of-pocket expenditure should not be incurred for public health services (Rannan-Eliya et al. 2012), there remain marked disparities according to wealth and urban-rural residency. Physical access to health facilities was found to be a dominant issue. While all districts had ambulances (Snell et al. 2005) they were often unavailable or limited by fuel shortages or poor maintenance (MAMA 2013). Wild (2009) concluded that in rural areas of the country, '*Transport costs are three times higher than the cost of health services*'. Currently, Timor-Leste has no existing models where transport costs are being reimbursed or paid.

Even if vehicles were readily available, roads were poorly maintained and floods and landslides, common during the wet season, were found to prevent access (Wild 2009; Wayte et al. 2008; Zwi et al., 2009; Dash 2003). Challenging travel conditions were found to significantly discourage attendance at health facilities for non-emergency and severe conditions. Communities were concerned that journeying to a health facility may actually contribute to the deterioration of a patient's condition (Zwi et al. 2009). Dawson et al. (2011) found that outside the capital Dili, 33% of the population lived more than two hours' walking distance from a health facility.

Much of the published literature suggests that women's reluctance to seek care often resulted from their reticence to face expressions of anger or expose themselves to blame from health workers (Wild 2009). From the demand perspective, Zwi et al. (2009) found that women had clear ideas about the consultation process they wanted. If, for example, they had travelled a long distance, they expected to be seen even if they arrived out of hours or without their registration card. It was widely reported, however, that providers behaved harshly towards mothers who presented late, had not washed before they arrived, whose children had not gained weight or who had not completed a course of vaccinations. In a USAID/Ministry of Health community consultation on child health practices (2007), mothers in Ermera and Bobonaro districts reported being admonished or turned away at health facilities because they went to the wrong facility or on the wrong date. The World Bank study (2006) found complaints of rudeness, preferential or negligent treatment by health workers and a lack of explanations for diagnoses and treatments to be common.

Health workers also reported challenges in their relations with patients. They resented what they perceived to be a lack of appreciation from the communities they served (Higuchi et al. 2012) and were frustrated by limited prevention practices and delayed treatment seeking that led to negative outcomes which they were then blamed for (Zwi et al. 2009).

Healthcare worker shortages and foreign doctors

The literature documents a shortage of skilled health workers and the poor distribution of human resources for health across Timor-Leste (Henderson and Tulloch. 2008). Estimates of the ratio of doctors to population ranged from 1:10,000 to 4:10,000 (Asante et al. 2011). The majority of trained midwives were clustered in urban centres and there was reluctance to work at rural health posts due to the challenging operational environment (Dawson et al. 2011). In terms of health worker to population ratio, Oecusse had a ratio of 1:1,874 compared to Baucau with 1:955 (Asante et al. 2011). The national rate of Caesarean section was far lower than that deemed to be medically necessary, with a Caesarean section performed in just 0.3% of live births, compared to an expected rate of 5-15% (World Bank 2006). This emphasises problems in accessing emergency obstetric care and the lack of qualified personnel. Other limitations that were reported included poor inter-facility communication and a lack of opportunities for training or continual professional development (Zwi et al. 2009).

The health system remains heavily reliant on foreign personnel, many of whom are unable to speak Tetun (Dawson et al. 2011). In 2011, two of every three doctors in Timor were part of the Cuban Medical Brigade, with a further 700 Timorese students scheduled to gain medical degrees in Cuba in cooperation with the Timor government (Asante et al. 2011). New graduates must serve in the public health system for a

minimum of six years or face huge financial disincentives (Cabral et al. 2013). Asante et al. (2011) found that many Timorese health professionals regard their work as contributing towards the rebuilding of the country and therefore do not expect much in terms of salary, whilst others count themselves to be lucky to have a job with a guaranteed salary, no matter how small.

Mother and daughter, Railaco, Ermera District

Demographic details

Table 2 – Compiled demographic details of primary caregivers interviewed

	Baucau (n=10)		Ermera (n=9)		Oecusse (n=9)	
Relation to child	Mother	10	Mother	8	Mother	0
			Father	1		
Employment	Unemployed	6	Unemployed	1	Unemployed	4
	Farmer	4	Farmer	5	Farmer	2
			Sales/market	2	Sales/market	1
			Student	1	Cook	2
Age range	(years)	20-40	(years)	18-25	(years)	19-40
Marriage	Married	10	Married	8	Married	9
			Single	1		
Children in care	No. of children	1-5	No. of children	1-5	No. of children	1-8
Religion	Catholic	10	Catholic	9	Catholic	9
Education level	None	4	None	3	None	2
	Primary	3	Primary	3	Primary	4
	Secondary	3	Secondary	3	Secondary	3
Average income range	Monthly USD	0-39	Monthly USD	10-500	Monthly USD	1-700
Recent child sickness	Pneumonia	2	Pneumonia	4	Pneumonia	2
	Diarrhoea	2	Diarrhoea	2	Diarrhoea	4
	P and D	2	P and D		P and D	
Newborns	No. of caregivers	4	No. of caregivers	3	No. of caregivers	3

Mothers in Baucau were aged between 20 and 40 years old and the number of children in their care ranged from one to five (including at least one child under five years old). Mothers in Ermera were aged between 18 and 35 years (the one father interviewed was aged 35 years) and also cared for between one and five children. In Oecusse, mothers were aged between 19 and 40 years and cared for between one and eight children.

All mothers interviewed in Baucau and Oecusse were married. Eight mothers in Ermera were married and one (the mother of a newborn) was single (never married). All were Catholic.

Education levels appeared fairly consistent across all districts with between two and four mothers reporting no educational history, three to four caregivers reporting at least some level of primary school education and three mothers per district reporting some level of secondary school education. No caregiver had tertiary level education.

Income levels were highly variable across both districts with differences in husbands' employment and the mother's education level being the most important factors determining higher income ranges.

Reported occurrences of pneumonia and diarrhoea (or children currently experiencing both) appeared to be similar across both districts and it was clear that participants had experienced repeated episodes of pneumonia and diarrhoea in their children.

Theories of causation, symptom recognition and prevention

Timor-Leste has incredibly diverse cultural traditions and practices, with different ethnic groups speaking a range of languages. Although Tetun was understood and spoken by all participants in Baucau and Ermera, in Oecusse, the primary language was Baikenu. Given this diversity, Table 3 presents a concise overview of the terms most commonly used by primary caregivers to describe diarrhoea, pneumonia and their symptoms, and birthing complications. These correspond to the symptoms most frequently identified and articulated by caregivers (rather than biomedical classifications). The terms used across the three districts include a range of local languages and dialects including Kemak, Makasae, Waimua, Kairui, and Mambae.

Table 3 – Terms commonly used to describe childhood illnesses and birth complications

	Baucau	Ermera	Oecusse
Diarrhoea	*na'i bere*	*tensali* *ba'ibrage* *té ben*	*tai ki namen* *opan* *tai menas*
Cough	*roso*	*tahu*	*bo'ho*
Cough with fever	*nasu roso*		
Fever	*nasu* *mutu*	*etaniri* *lolobansa*	*ao nin maputu*
Fever with shivering			*nabubu*
Runny nose	*nu hora*	*ilu eran* *ilu sali*	
Difficulty breathing	*hamanai*	*mren sai*	*sas' ni n'ateta*
Not breathing		*lis laiha*	
Dizzy			*mat ki naen* *ne ki nam ne`uk*
Headache		*guturenba*	
Breech birth		*ain mai uluk*	
Placenta comes before child		*foer mai uluk*	
Bleeding from the placenta		*ran sai husi husar*	

When asked about common illnesses affecting children in Timor-Leste, caregivers in Baucau listed diarrhoea, fever, malaria, running nose, difficulty breathing, coughing, low birth weight, malnutrition, respiratory infection, skin disease, and swollen stomachs. The most dangerous conditions, according to mothers, were diarrhoea and difficulty breathing. Regarding common birth complications, bleeding, lack of strength, breech births and 'family problems' were most frequently mentioned. 'Family problems' refers to the widespread belief that social transgressions or family arguments can result in certain types of spiritual sickness that may harm or kill children (discussed further below).

In Ermera, the most commonly reported child illnesses were coughing, fever, diarrhoea, congenital birth defects, itchy skin, stomach ache, running nose, and difficulty breathing. Consensus did not exist among mothers as to which illness symptoms were the most risky or dangerous. One mother suggested that fever and diarrhoea were the most dangerous.

For diarrhoea, sometimes they only get it for one or two days but to look at the child it looks like they have been sick for a week. When mothers see this it makes us scared because the child looks like this. For fever, they are too hot. Burning up. So it seems as if they are going to die. This is why these are the most severe.

Another mother suggested fever and coughing to be the most dangerous.

For me, the fever and coughing is the worst because when he is coughing he doesn't sleep. For like diarrhoea it is not so dangerous for me because sometimes it only lasts for one or two days… But the coughing is the serious sign because at night he doesn't sleep. He doesn't sleep well when he is coughing so much.

In Oecusse caregivers described difficulty breathing, diarrhoea, fever, stomach ache, shaking, coughing, chicken pox, headache, running nose and malaria as the most common children's illnesses in their area. Diarrhoea, vomiting, malaria and *bungkolo maten* (seizures, body shaking) were perceived to be the most dangerous symptoms for children to exhibit.

Pneumonia

Caregivers' knowledge of pneumonia symptoms was overwhelmingly concentrated on coughing and fever. Additional symptoms identified, although with less frequency, included loss of appetite, difficulty breathing, running nose and vomiting, expressed as '*throwing out mother's milk*'.

When asked to describe pneumonia, caregivers would articulate specific symptoms, usually cough and fever. This had implications for how caregivers understood the cause and recognised the condition of pneumonia. Frequently, the earliest sign of pneumonia was perceived as an individual symptom that was not dangerous until a subsequent symptom emerged, by which time the illness was likely to have progressed. The interpretation of symptoms therefore influenced care-seeking behaviour, and often led to delays (discussed further below).

In Ermera and Baucau, caregivers suggested that pneumonia was caused by dust, strong wind, heat, unclean vegetables, eating before washing hands, drinking unclean water and seasonal temperature changes. Two breastfeeding mothers also thought their child's pneumonia may have been caused by something they (the mother) had eaten. Only two mothers interviewed had 'no idea' what caused pneumonia. The most common explanations were dust, heat and drinking un-boiled water. A mother in Baucau whose child had recently had pneumonia explained, '*He was playing with the dust, playing under the heat, and he took un-boiled water, dirty water. When he is playing, he takes things that he wants, it makes him have the coughing and fever*'. A mother attending her 7-year-old child who was hospitalised with pneumonia at Gleno Hospital, Ermera suggested,

Maybe her illness is caused by the heat, because she goes to school every day and she leaves the school in the afternoon and has to walk three kilometres from the school back home and it is very hot… And also when she reaches home she is a naughty girl, when we tell her to rest she doesn't want to rest. She goes and plays and gets tired.

The attribution of pneumonia to dust and strong winds explains why most caregivers in Baucau and Ermera described an increase in the number of symptoms of pneumonia during the dry season. There was, however, little consensus over the timing and progression of the illness.

In Oecusse, respondents did not ascribe pneumonia with the same casual factors as in the other two districts. Although dusty air quality and drinking un-boiled water were mentioned by a number of caregivers, the majority stated that children 'falling down' or being carried 'wrongly' by mothers or older siblings were the most common causes of pneumonia. Unlike in Baucau and Ermera where coughing was linked to pneumonia and connections were made with 'a wound in the lung', in Oecusse, a child's difficulty in breathing was instead attributed to an external accident that caused the pain in their chest. A mother in Passabe, Oecusse, explained, '*His brothers and sisters sometimes carry him. When I went for carrying water and came back, suddenly I saw the baby having difficulty breathing so maybe he was carried wrongly…Sometimes we put him on the seat and he falls down*'. Other statements such as '*sometimes we*

carry the baby in a rush' or '*sometimes we carry the baby in the wrong position and the baby's bones get broken*' were common.

Caregivers in all three districts, particularly those who had encountered health workers during the course of their child's pneumonia, suggested common forms of prevention associated with avoiding dust and dirt. A mother whose child was hospitalised with pneumonia in Gleno Hospital, Ermera, explained, '*I was advised by the doctors not to let the children play with dirty water and dirty things, they should be clean and they need to eat well and drink water*'. Similarly mothers in Baucau, suggested, '*I was told to prevent the child from playing in the dirt and with dirty things*'; '*They advised me not to let the child play in the dust*'; '*They said to keep the baby away from dust and wind and not to bring the baby out of the house*'. Given the environment most families lived in (homes with thatched roofs and an earth floor, often close to dusty unsurfaced roads), mothers did not know how it was possible to prevent their children from being exposed to dirt and dust.

Health workers at Ermera Lama clinic also suggested that a common cause of childhood pneumonia in their area was the practice of a mother and newborn staying close to the fire immediately following birth. In such cases, pneumonia was thought to be caused by inhaling the smoke from the fire. Interestingly, this was not forwarded as a cause of pneumonia by caregivers. The practice is discussed further below.

Diarrhoea

Caregivers discussed a wide variety of symptoms they associated with diarrhoea including watery stool, high fever, trembling/shaking, eyes that moved around too fast, sunken eyes, too much saliva in the mouth, wounds inside the mouth, swollen stomach, loss of appetite, physical weakness, frequent crying, sleeplessness at night and sleeping too much during the day. The signs that indicated severe dehydration (wounds in the mouth, sunken eyes) were only suggested by mothers of children who were hospitalised with diarrhoea at the time of interview.

Across the districts, there were three commonly reported causes of diarrhoea: breastfeeding mothers eating food that was not suitable for children (including young corn, red beans, the tops of sweet potato); children 'being naughty' and eating 'wrong' or unripe fruit (for example, mangos, tamarind); and not washing picked fruit before eating. A mother in Baucau thought her son's diarrhoea had resulted from her breastfeeding him '*for too long*' (seven months) whilst a mother in Oecusse recalled that her newborn's diarrhoea had started as soon as she began to breastfeed. Caregivers in Ermera also listed eating unclean vegetables and teething as common causes of diarrhoea. Attribution of diarrhoea to crops that are 'young' or 'unripe' explains why the majority of caregivers described the number of cases of diarrhoea increasing during the wet season. As a community health volunteer in Railaco explained,

> *The rainy season is November from April to May, but diarrhoea usually happens in the first three months from November to January. This is the season where the diarrhoea mostly happens, caused by eating the crops that are grown from the new rain… It is because the vegetables that are grown from this rain are not pure. For example, spinach or mustard… The dry season has been so long, the first rains that come for the rainy season are not pure and need time to purify before the crops that are grown from them are clean.*

In contrast to the robust list of symptoms, methods of prevention were not widely known, and most mothers claimed to have 'no idea' how to prevent diarrhoea, often '*because it happens suddenly*'. Only two mothers discussed prevention strategies. One, in a focus group discussion in Vemasse, claimed that she washed food before cooking it to prevent diarrhoea. Another mother in Baucau, whose children experienced frequent bouts of diarrhoea, suggested that she would 'avoid giving foods that cause diarrhoea'. When a mother whose child was hospitalised with diarrhoea in Baucau was asked if a doctor or nurse had informed her how to prevent her child from getting diarrhoea again, she responded, '*The doctor did not say anything. But as mothers we have to know to prevent this. Maybe the doctor will inform me before we go home*'.

Caregivers were also questioned about household water sources, sanitation and hygiene practices. In Baucau, '*if there is water*', the most commonly cited sources were government pipes or, if the pipes were dry, wells. Pipes would frequently run dry in the afternoons during the dry season and, as one mother in Venilale explained, '*sometimes there is no water for a week*'. All participants in Baucau reported boiling their water before drinking. A mother of a newborn baby in Vemasse suggested, '*We usually boil the water before drinking, because we can get a cough if we drink it directly*'. Another mother attending Baucau Hospital to treat her child's pneumonia and diarrhoea confirmed, '*We had information from SISCa to boil the water first to prevent sickness such as diarrhoea and coughing. We need to boil the water in order to kill bacteria*'. The most common type of sanitation in Baucau was a pit latrine, although one mother suggested that adults would also defecate in the pig cage. Because '*small kids just go anywhere they want when they are small, you can't instruct them*', the most cited method of disposing of a child's faeces was to allow dogs or pigs to eat them. Hand washing with soap was most commonly reported to occur before eating, after going to the toilet and after working.

In Ermera, the most common source of water was through the public pipes, and only one mother reported using a well. Boiling or straining water was common and no interviewee discussed drinking water directly from the pipe. As one mother in Railaco explained,

We draw the water from the pipes but at the source of the water there is a big tank that is open. When the rain comes, the dust or the dirty leaves can get inside the tank and so when the water comes sometimes it is dirty… For me it is dirty water. Sometimes the water is mixed with the soil, but this is our only water source. When we draw the water we have to strain it and after this we boil it.

There were two main sanitation systems in Ermera: open pit latrines covered by palm leaves; and cement toilet structures with a water collection tank and a large spoon for scooping water to 'flush' the toilet. One in Railaco explained that the government had built a cement toilet structure for her and several other families in the area. As in Baucau, children's faeces were usually not cleared but left for dogs or pigs to eat because '*before the age of three, children go anywhere*'. Hand washing was reported to happen before eating and after going to the toilet. If soap was not available, then washing detergent would often be used.

In Oecusse, the most common source of water was the government pipes, although only half of the caregivers interviewed reportedly boiling water before drinking, and no one discussed filtering methods. A mother from Pante Makasar explained, '*When we feel thirsty we just take the water from the well and drink, we never boil the water*', whilst another in Passabe stated, '*We should boil the water, but sometimes when we go to the farm we drink the water directly*'. Although pit latrines covered by palm leaves were common, many caregivers also discussed defecating in the open '*out by the garden'*. Again, children's faeces were left to be eaten by dogs or pigs. A father in Pante Makasar concluded,

There is no proper toilet, people just go anywhere for the toilet and sometime children step on people's shit and don't wash their foot. Children don't use shoes or slippers. It can cause malaria or diarrhoea, because of flies from the shit.

Hand washing was reported to occur most often in the morning, after work or before eating, although the use of soap was variable, '*sometimes we use soap, sometimes we forget'*.

<u>Pregnancy and birth complications</u>

In discussing pregnancy and birth related complications, the initial response from most mothers was '*I don't know what goes on in my neighbour's house*', highlighting not only the frequency of home births but also the level of privacy that is maintained, despite close living quarters. When questioned further on their personal experiences of pregnancy and birth, women described complications they had experienced including: high blood pressure; swollen breasts; bleeding; children born with blue skin who had difficulty

breathing; improper positioning of the child for delivery; and difficulties with regards to placentas (either being retained or coming out before the child).

Traditional birth attendants (TBAs) in Baucau confirmed that incorrect positioning of the baby in the womb and the placenta coming out prematurely or being retained after birth were problems they frequently experienced in their work. TBAs in Oecusse also suggested that a woman's womb could be in the wrong position and this necessitated them using traditional medicines to correct its placement (discussed further below). A TBA interviewed in Ermera confirmed that common problems she encountered included 'children being born with breathing difficulties', 'closed cervixes' and breech births.

When the father came to get me and I went to the mother one foot had already come out. I told the husband to bring her to the hospital but the husband did not accept this so I was trying my best, because I cannot return the foot inside so I was using my hands to try and get the other foot to come out. I was trying and trying and eventually the baby's hips came out and the shoulder and the head were getting stuck. The whole body of the baby was becoming black and the whole head was still inside the womb and the baby was making these gasping noises like she could not breath. Everyone was getting so scared so I just prayed and prayed to God to help me remove this baby's head. Everyone was so scared of the baby's black coloured body.

Perceptions of risk associated with labour and childbirth were varied. A mother in Oecusse described *na mutin* (white blood, potentially lochia) as something she had experienced after giving birth to all her children and was therefore normal, '*White blood can affect the woman to get dizzy, head ache, cold. That's what we call na mutin, but I think it is because there is lack of blood after giving birth…too much blood loss*'. Another mother in Baucau who had given birth prematurely to twins, and one neonate had died in hospital, was asked if she had experienced any pregnancy or birth complications, but her response was simply 'no'. This did not appear to be a strategy to avoid discussing personal events, rather that the mother did not link the death of her child to pregnancy or birth complications.

The only complication that mothers perceived to have a discernable prevention method was the position of the baby in the womb. In order to prevent breech births, several precautions or courses of action that the mother should take were listed: not riding motorcycles or horses; visiting an *a samat* (traditional masseuse); having a traditional birth attendant check and move the child into the correct position. Although this was a common practice in all districts, the timing of when expectant mothers should have their children turned was highly variable. In Oecusse, some women visited an *a samat* on a daily basis throughout their pregnancy, whilst in Baucau, women typically had their children turned only in the final weeks or days of pregnancy.

In both Baucau and Ermera, the cause of pregnancy and birth complications was mainly attributed to the hard physical labour mothers continued to perform in the months leading up to delivery. The mother of a newborn interviewed in Baucau explained,

I was told [by hospital staff] that I got sick because before I was pregnant, during the six months before pregnancy, I didn't menstruate. I didn't get my period for six months and then when I did finally get it I got pregnant…The nurse and the doctor who check-up on me said that I need to eat well and don't do hard jobs when I am pregnant. That I need to sit down, don't force myself to do heavy things like that. And for the next time I am pregnant, don't do all these things because it's dangerous.

This mother's comment regarding her missed periods is likely a reference to amenorrhoea (lapsed or absent menstruation) caused by a physically intense lifestyle (which may also cause lactational amenorrhoea).

In Ermera, difficult working conditions was the most commonly cited cause of birth complications and it was understood that expectant mothers who worked too hard and did not have proper nutrition during

their pregnancies would have low-birth weight babies. Other conditions resulting in birth complications included high blood pressure and the baby being too big for a smooth delivery. A mother in Ermera Lama explained,

The challenge for me was when the baby was eight months old in the womb, I got hypertension and my feet and hands were swollen. And both of these things happened at the same time… And so when the baby was going to be born I was told the baby was going to be operated [Caesarean section] because the baby's weight was more than four kilos. After the birth I felt the stitches were painful.

The father of a child with pneumonia admitted to Gleno Hospital, Ermera, described the death of his first child from suffocation. He recalled that the baby had been born with a 'sac-like thing' covering his head (likely a portion of the birth membrane).

We did not know how to remove this thing… My wife was hugging the baby for one hour and then after that he passed away because we did not know how to remove what was covering his face. The next day we brought him to the clinic who told us we were supposed to call a nurse or midwife to remove this from the child's head. That if we had called them, they would have removed this from his head and he would have lived.

Such cases highlight the lack of skilled attendants at home births.

Local theories of causation

In Timor-Leste, culturally bound illnesses and local theories of causation remain strong. Although attributed to specific conditions, symptoms sometimes overlapped with those that may indicate pneumonia, diarrhoea or potential birth complications. In relation to local illnesses such as *vistidu*, *bungkolo maten*, *horok* and *rai kutun*, biomedical intervention was often thought to be inappropriate and unable to cure the condition. Instead, traditional healers or *matan dook* (a specific type of traditional healer capable of diagnosing spiritual sickness) were to be consulted. (Local healing traditions are discussed further below).

Vistidu, described by caregivers in Baucau and Ermera, was a condition characterised by febrile seizures. Children with *vistidu* experience a high temperature, they shake or jerk their arms and legs on both sides of the body, their eyes roll back in their head and they may lose consciousness. This was known to be a condition that could quickly kill children, within minutes or hours after the seizure suddenly began and was caused by the child being possessed by a bad spirit. Treatment of *vistidu* involved burning a piece of black cloth close to the child's nose so they inhaled the smoke. The cloth was the type of material people wear around the wrist, neck or head to honour a family member or close friend who has died. Typically, the closer the relationship, the more cloth is worn to cover the body and for an extended period of time (from six months to a year). In addition to inhaling the smoke from burning the mourning cloth, a poultice of garlic and oil (potentially mixed with other local plants) would be massaged into the child's body. A mother interviewed in Vermasse, Baucau, described how two of her children had been killed by *vistidu*. Her son died when he was six months old. The *vistidu* had started at 6am and two hours later he had died. Her daughter caught *vistidu* when she was three months old. They '*took her to people who know about it, not to the hospital*', but within a few hours of seeing the traditional healer, she too had died.

In their focus group in Pante Makasar, fathers described the condition *bungkolo maten* or shaking sickness that occurs in Oecusse. Like *vistidu*, *bungkolo maten* presents with sudden and violent body shaking, yet it was seen to be distinct from *vistidu* in several ways. *Bungkolo maten* is an illness that both adults and children can contract, although it is more dangerous for children. It is thought to be contagious, and although biomedical treatment may be sought, it is not efficacious. Fathers in the focus group explained,

Father 1: *This kind of sickness, when the baby gets it then the baby dies, or it will sleep for a long time. Even when we bring the baby to the clinic or hospital, it's the same. There's no medicine there to treat the baby. And this sickness will spread to others.*

Father 2: *It happened to my second child for three days. I was afraid and brought the child directly to the hospital in Oecusse. The fifth child also had the same thing.*

Horok was described as a type of illness caused by bad magic that usually results from the shameful behaviour of the person afflicted. It was explained as follows: a person who owns fruit trees may put *tara bandu* (a small bundle of sticks imbued with spiritual power by a *matan dook*) to protect the trees. If another person takes the fruit from the tree without permission, they will get *horok*. In describing the causes of childhood diarrhoea, several mothers suggested that children were 'naughty' and ate 'wrong' food. This explanation covers multiple causes, firstly that children were eating unclean or unripe fruit, and secondly, that children were eating food that did not belong to them, thus resulting in *horok* which presented as diarrhoea.

Health workers at Ermera Lama clinic also described patients who attributed their child's pneumonia or diarrhoea to spiritual causes including *horok* or *rai kutun*. *Rai kutun* literally translates as 'earth bug' and was thought to be a spirit that can cause sickness to children who pass too close to where it is living. In their focus group discussion, health workers in Ermera Lama suggested that local theories of causation often prevented parents from seeking biomedical treatment in a timely manner.

Chief of Health Centre*: This is a very common practice because we don't usually see these babies here in the health centre until three days or sometimes more than one week after the sickness started. That tells us that people are doing something to their children at home. For example for pneumonia, people believe that their children get sick because one child is eating a biscuit and doesn't give to their brother or sister and so that child got sick because of horok. Another example is saying my child got sick because of that person, and they are pointing to someone they say is a witch. Because the person is a witch they made my child get sick.*

Midwife*: Sometimes they call rai kutun, a living spirit in an area. When you pass by their area, maybe this area is considered the place or the home of a rai kutun and then maybe you pass by the place and that rai kutun makes the child sick. This is for pneumonia. Or for diarrhoea they have something they call horok bee kadoras. For example, now I have an orange tree with a lot of fruits so on this tree I tie a small bunch of grass together with a small bunch of wood and hang this on the tree. Before I put it there I was praying over it to give it the power to make it strong so that if you pass by and take one of my fruits from the tree without asking my permission then this horok will make you sick. So for diarrhoea, people have a suspicion regarding this cause.*

In relation to potential birth complications, TBAs in Passabe, Oecusse, advised mothers not to sleep on their backs until after the fourth month of pregnancy. It was thought that when sleeping on her back, a mother's blood would be forced to divide with half running along the left side and half along the right side of her body. For pregnant women, this could cause one child to divide into twins. After the fourth month, however, the baby was considered to be firmly established, and women were therefore able to safely sleep on their backs. As a TBA concluded,

We tell pregnant women, don't sleep on the back because you will have two babies. The limitation is up to 4 months of pregnancy, then the woman can sleep on her back, but in second month of pregnancy, what is inside is still blood and it can separate and become two babies. First and second month she should sleep on her side.

Mother in front of incubator holding her 3-week-old daughter, Baucau Hospital, Baucau Distict

Care-seeking behaviour and practices

The following chapter outlines care-seeking behaviour and practices in relation to the multiple sources of care and treatments available in Timor-Leste. It should be noted, however, that pathways of care often overlap and care-seeking is highly flexible and pragmatic, not a linear or concretely defined process. As a father in Pante Makasar, Oecusse concluded when discussing care-seeking for his child with pneumonia and diarrhoea, '*We find a way to get medicine to cure the baby. We burn candles for grandfathers and grandmothers who have passed away and we pray to God*'.

Plant medicine and home remedies

Aimoruk Timor (Timor medicine) was traditional, plant-based medicine, and was described in all three districts. Leaves, bark and roots were the most common ingredients, although most participants were unable to catalogue the names of plants used. An exception was the use of the candlenut tree that was frequently specified by caregivers. Both the green leaves and nut (*kami*) were used, the latter due to its high oil content making it an important component in poultices to be massaged onto the skin. Common cooking ingredients such as garlic, ginger and pepper, and in Oecusse, pomegranate and guava were often added to medicinal mixtures.

For women experiencing a long or difficult labour, or mothers who had recently given birth, Baucau traditional healers often prescribed massages with candlenut oil, or advised their clients to boil its leaves and roots in water and then either drink the warm water or bathe in it. A TBA in Venilale, Baucau, explained, '*We just use candlenut and water to rub on mother's belly in order for the belly to be soft or rub on the back of the mother. We do this when delivery is late*', whilst another in Vemasse, Baucau, confirmed, '*After birth, the mothers used to ask how to have a healthy condition for the baby and the mother. And I advised them to take bath with warm water and drink warm water that is mixed with certain kind of leaves and roots*'.

Plant medicine was also used by a mother in Venilale to encourage the production of breast milk. '*Sometime after giving birth, if I go the whole day with no breast milk, then my husband will go and find aimoruk Timor to cook together with corn or porridge and I will eat it to get the breast milk*'.

Aimoruk Timor was also used to treat child illness, particularly breathing problems and to reduce fevers associated with pneumonia. A mother in Venilale described,

> *We heat candlenut, mix with garlic then rub on their neck and forehead… If it doesn't help then we take them to the hospital to get medicine, and if that doesn't help too then we do something else such as boil papaya leaves, ginger and pepper and mix with sasoro (porridge) and give to the children to help release the phlegm.*

For children experiencing diarrhoea, a mixture of water, salt and sugar would be given to children. ORS and its home-made version were often the front line treatment for diarrhoea. In their focus group discussion, health workers in Ermera Lama confirmed that parents often treated diarrhoea at home with the homemade 'Oralite', particularly if clinic supplies were low, but remarked how dangerous this could be if diarrhoea symptoms remained or intensified.

> Chief of Health Centre*: Sometimes when they bring the children here in the health centre with diarrhoea parents will tell us we already gave Oralite which they make of water, salt and sugar to give to the baby.*
>
> Doctor*: For Oralite they can make it themselves because for those who come to the health centre we would explain about this treatment and we give them examples on how to do it. But the differences is that some*

people may give the wrong measurement and mistakes are made in the measurement so the balance is not equal to what they are supposed to do and this causes the children to not get better.

According to health workers in Ermera Lama, the correct measurements for homemade 'Oralite' was '*one glass of warm water, not so hot and not so cold, plus one tablespoon of sugar and then use the opposite end of the tablespoon to get a little bit of salt and then you mix this together'*. Mothers and fathers in Pante Makasar, Oecusse, also described following clinic instructions to prepare homemade ORS substitutes using sugar, salt and boiled water. Often the homemade ORS solution would be given in parallel with *aimoruk Timor*. A mother in Gleno suggested, '*The nurses were the one advising us that if this medicine doesn't help you need to go home and get these leaves to give to the baby to take. And if you do not do this then prepare tea for her with salt for her to drink'*.

Whether or not plant medicine was used as the first line treatment for child illness was largely determined by how close and easily accessible the nearest health facility was. If the facility was far, or health staff were unavailable, for example when clinics were closed on Saturday and Sundays, then children were most often treated with *aimoruk Timor*. If their condition was not severe, caregivers in Baucau were likely to wait from one to three days to see if the plant-based medicine worked before seeking additional assistance. In Ermera this waiting period was generally three days to one week. As a mother whose child was admitted with pneumonia to Gleno hospital recounted,

It was on Friday that the high fever started and Saturday and Sunday was the weekend so the clinic was closed. Her father went and found some leaves and things to boil and give her a bath with the leaves. In the evening of Monday the high fever was reduced and she started to get cold. But yesterday morning the fever started again, so I asked for her to be brought to the clinic.

A mother in Railaco, Ermera explained,

We just find leaves of any tree and we use them. When the babies are feeling too hot and we come to the clinic the nurses will not give us medicine. So we use the traditional medicine to reduce the fever first and then we bring them to the clinic for treatment.

This statement references the belief that if caregivers presented their child at the clinic with a fever, the nurses would chastise them for allowing the children to become so sick before seeking treatment. It was common, therefore, for caregivers to treat a child at home in an attempt to reduce their symptoms before taking them to the clinic, in order to avoid perceived criticism from health workers. Forwarding the perspective of the health worker in relation to this practice, staff from Ermera Lama clinic concluded,

If they did already some traditional treatment at home, the mother and father are busy with their farming, doing their daily activities. Early in the morning they go to the farm and when they come back in the afternoon it is already too late. They don't pay much attention to their child, they just let the children stay at home and after three or four days or one week when they look at their child's condition then it is already too late.

A samats*, traditional birth attendants, healers and *matan dook

Across the three districts, it was common for participants to distinguish between four different types of traditional healers: those who assisted women during their pregnancy, primarily through massage (*a samat*); those who assisted women during labour (traditional birth attendants); those who made medicines from local plants for curing illnesses or broken bones (healers); and those who determined and treated the spiritual causes of physical illness (*matan dook*). Each is described in detail below, however, it should be noted that whilst it was possible for one individual to perform one or more of the different functions, each of the four roles was seen to be distinct and regarded as a specific pathway of care.

A samats

A samats were most commonly utilised by pregnant women in Oecusse to perform the specific function of massaging the stomach prior to birth to ensure the baby is correctly positioned and can be easily delivered. Only one mother in Oecusse, in the sub-district Oesilo had never visited an *a samat* during her pregnancy, although she had received antenatal care from the local health facility. Mothers would often list two or three *a samats* who lived in close proximity and who they would visit when necessary. Whilst all TBAs described performing the role of an *a samat*, not all *a samats* were TBAs.

The timing and frequency of visits to the *a samat* were highly variable. Most women described only starting to visit an *a samat* during the seventh month of pregnancy, although others were massaged every day from discovering they were pregnant until they delivered. This was also the instruction given by TBAs in Passabe, who advised '*Massage every morning as soon as she gets pregnant until nine months'*. A mother in Pante Makasar suggested that the easy availability of the *a samat* in her mother's home village was one of the reasons she moved from Dili to her maternal home during her pregnancy. She explained, '*I was alone while my husband was in the military compound. There was no one taking care of me, so I thought it was better to come to my family to get cared for and where I could go to the a samat for massaging*'. Another mother from Pante Makasar also suggested that *a samats* could, on occasion, cure children's diarrhoea, '*For some children with diarrhoea it can be healed only with massage without any medicine*'.

Traditional birth attendants

Traditional birth attendants have long been an important source of healthcare for both pregnant women and during delivery, particularly in rural areas where the population has limited access to government health centres. Across Timor-Leste, TBAs are both male and female. National statistics on the ratio of male to female TBAs do not exist, however, for those enrolled in this study (n=10) 50% were male and 50% were female attendants.

Throughout Timor's recent history, there have been several interventions aimed at training TBAs, particularly in clean and safe deliveries. Not all TBAs involved in the study had received training, and one claimed never to refer mothers to health facilities but to manage pregnancies and deliveries with a degree of autonomy. In contrast, a female TBA in Gleno, Ermera, recalled that she first learnt how to assist women during childbirth from a Portuguese doctor during the 1960s. She described this doctor as a 'respected brother' who taught her medical practices she otherwise would not have '*had an opportunity to learn*'. During Indonesian rule, this TBA attended a three-day training seminar at the local hospital in accordance with Indonesia's National Health Policy on TBA training. She was excused after the first day of training – with a completion certificate – as her knowledge and experience exceeded the level being taught to other workshop participants.

TBAs in Passabe, Oecusse, described having beneficial working relationship with the local clinic 'since Portuguese times'. Although this was seen to be positive in terms of collaborative service delivery, there remained times when biomedical and traditional practices clashed. For example, the TBAs knew that doctors vaccinated a child immediately after birth, but they felt this practice should be delayed until the mother's *na mutin* (white blood) had cleared. Several of the TBAs who participated in the focus group discussion were against family planning and many continued to advise new mothers to practice *tur ahi*, staying close to the fire with their newborn for several weeks after birth (discussed further below).

Since Independence, training of Timorese traditional birth attendants has been actively opposed in favour of facility-based deliveries. The national Health Policy Framework from 2002 (Ministry of Health 2002) outlined the medical model as 'The only rational choice for birthing services' (Wild 2009:33). The SISCa programme has provided health education to TBAs, informing them about the advice they should give and the practices they should *not* follow, rather than providing training for skilled attendance. A male TBA in Venilale, Baucau, recalled that after he had attended a session by SISCa in 2009, where the practice of *tur*

ahi was explained to be harmful to the mother and newborn, he had been encouraged to dissuade women from continuing this customary practice. This policy towards TBAs presents an interesting tension in which the SISCa programme targets TBAs to provide information to mothers, thereby recognising the influential standing TBAs have in the community, yet actively discourages them from providing the care which led to that status.

The availability of TBAs differed across districts and sub-districts. In Baucau, mothers in Vemasse could list four TBAs, whilst in Venilale the number ranged from two to five. Here, all participants emphasised that the TBAs were well known to the community and that if a women wanted assistance from a TBA, everybody would know where and who to ask. In Ermera, only one TBA was reported in Gleno and one in Ermera Lama. All the TBAs interviewed stressed that they assisted with births in the woman's home, but only after being requested to do so by the woman or her family. A TBA in Railaco explained,

For Timorese people, we know each other. You don't need to tell them what you do, you don't need to tell people what it is you do. People will think you are trying to advertise your services and I don't like this kind of thing. They come and call me to go to their house, but I don't offer my skills. If you tell Timorese people you have the skills to do these things then later on they will say you come here just to make us interested in what you do. I never, even if I know someone is going to give birth, I don't advertise. They come to me to ask for help.

In Oecusse, the one occasion when women would visit a healer's home was for massage from an *a samat* during pregnancy. Childbirth would always happen in the woman's own home. In addition to massage, some TBAs also prepared traditional medicines (for example, to reposition a woman's womb as mentioned above). The preparation of these medicines was the TBAs' private knowledge and would '*only be passed on to our own children when we are about to die*'.

Whether or not TBAs referred women to health centres during difficult labours was again highly varied across study sites. In Baucau, for example, the TBA in Vemasse never referred women to other care providers. She confirmed,

I never transfer women to anybody. For example, there were some babies born where the feet come first and I try myself to make the position better and the baby was able to be born. Sometimes mothers cannot breathe and I help by pushing, using my palm to make the mother breathe.

In contrast, the (male) TBA in Venilale claimed only to assist when labouring women were unable to reach the hospital in time. Within the previous two years, the majority of services this TBA had provided to mothers was massage, to move the baby into the correct birthing position, and emergency assistance related to the removal of retained placentas when women had given birth at home and were experiencing post-partum difficulties.

In Ermera, the TBA in Gleno would assist women in labour when she was requested to do so, but if she decided the birth was going to be prolonged or complicated, then she would refer them to hospital.

Some women, they know that I know how to help with birth, and some women when they are seven months pregnant ask me to go and see the baby's position to make sure it is ok. I will help to turn the baby down so that it will be easier to give birth. For some they only come for me when they start to feel the labour pain. For those who wait until it is time to deliver and the baby is not in a good position, then I refer her to the hospital to decide what to do.

Amongst TBAs who were prepared to refer their clients to the hospital, weakness or lack of strength to push were perceived as danger signs that would encourage their referral.

In Oecusse, more so than in either of the other two districts, it was common for a labouring woman to be attended by her close relatives (mother, father, husband, aunt) rather than assisted by a TBA or health staff. It was also notable in Oecusse, particularly in the sub-district Passabe, that the TBAs had a close working relationship with the local clinic. One TBA explained, '*If a woman delivers in the clinic and gets a problem then we will be called there to help, and if a woman delivers the baby in her house and gets complication then we will go to get the doctor to help*'.

In discussions with health workers, community and religious leaders, it was evident that the majority of women who had a facility-based delivery did so because their homes were close by and the facility was easily accessible. It was therefore accepted that women who used the services of TBAs did so because they lived in distant rural areas that were inaccessible by car or ambulance, and often in more mountainous regions. Interviewing the TBAs (with the exception of the TBA in Vemasse) necessitated the research team to navigate steep and rocky pathways that would have been perilous in an emergency situation. A *Promotor Saude Familia* (Family Health Promoter) in Venilale confirmed, '*People who are living far away have no choice so they go to traditional assistant. The traditional birth attendant can help pregnant mothers to deliver, or give massages to put the baby in the right position*'. In contrast, the village chief concluded,

As community leaders we have to advise that pregnant mothers should go to a SISCa programme, it is an obligation to go to SISCa programme and to deliver babies at the hospital. It is not right if mothers deliver at home with the help of traditional assistant, the mothers can get advice from the traditional assistant but they have to give birth at the hospital.

Traditional healers

In Baucau, participants frequently described visiting traditional healers (for both themselves and their children) to seek treatment for fever, coughing and diarrhoea. If caregivers had used *aimoruk Timor* or plant medicines as the frontline treatment, then traditional healers were most often the second source of care if a child's condition did not show signs of improvement. Again, this was also influenced by the distance between the caregiver's residence and the closest health facility. After giving home remedies, most caregivers stated that they would wait between one and five days before consulting a traditional healer. The healer would then use a combination of plant medicine and massage to treat the child.

Ermera Railaco residents stated they only had traditional birth attendants in their sub-district, but no healers. Residents in other sub-districts of Ermera and throughout Oecusse did not describe visiting traditional healers for childhood illness, although many did describe a friend or relative who had sought out traditional treatment. It can therefore be assumed that healers are present in all districts, even if they were not frequently accessed by caregivers in the study's sample.

Matan dook

Matan dook are a type of traditional healer in Timorese culture whose specific function is not to cure illness through the use of plant medicines, but by diagnosing the spiritual causes of an illness. *Matan dook* were also said to be able to foretell the future regarding sickness or death that had not yet occurred.

If a child's condition was deemed appropriate for intervention by a *matan dook*, they could be consulted before the child saw a doctor, to correct any lingering spiritual sickness thereby making the subsequent biomedical treatment more effective, or after visiting a doctor, if the biomedical treatment had not worked. A community leader from Venilale (a member of Parliament) compared the advice given by *matan dook* to that given by a doctor.

For example, if you have high cholesterol then you should avoid eating certain foods, and if you follow that doctor advice then you can get better. If you have a problem in your family then you fix it by following the matan dook advice and then you can get better.

However, a priest in Venilale, Baucau, explained,

I can tell you from experience that many people tend to go to traditional healers when they get sick. By sacrificing an animal such as a chicken, the traditional healer can quest [divine] *to determine the cause of sicknesses. So, traditional healer first, then doctor. When the traditional healers do not help then people go to the doctor, but many times when they see the doctor it is too late and the sickness is at a severe stage. The doctor can't help anymore and then the doctor will be blamed.*

A nun in the Canocian Community in Baucau confirmed that in most rural areas, people tended to visit traditional healers and *matan dook* due to their proximity. She voiced her frustration with these practices, particularly regarding the *matan dook* whom she regarded as making fraudulent claims about spiritual knowledge.

People prefer to go to the doctor but instead must first go to traditional people. I appreciate people who have a talent, like charismatic people, who use their own way to heal some people like praying. I agree with those people, but not to those who are illiterate, who have no knowledge of medicines… For traditional healers there are two kinds. One are people who can cure others by using leaves, roots and other things provided by nature and practised by our ancestors a long time ago, before doctors. And the other one we call matan dook which is someone that causes people's sickness.

This view was echoed by several caregivers. One mother who was admitted to Baucau Hospital with her child recounted how her brother became ill and a *matan dook* told him to fix the illness. The *matan dook* would not let her brother see a medical doctor and he died. She stated, '*I believe that when I come here [to the hospital], I always get better. The traditional healer is always telling lies*'.

Health facilities and the SISCa programme

As discussed above, living in close proximity to a health facility that was easily accessible was a positive determinant for seeking professional care. A nurse in Vemasse, Baucau, confirmed,

Some communities that are living far in the remote areas where they don't have access to healthcare, this will cause them to use traditional medicines but for those who are living near to health centre they are accessing healthcare.

The widespread coverage of SISCa programmes and their penetration at the community level has markedly increased rural populations' access to health services across Timor-Leste. In all three districts studied, the staff of the SiSCa programmes, who were sometimes referred to by the Indonesian term '*kader kader*', were regarded as frontline primary healthcare providers, particularly for antenatal care and child vaccinations. SISCa programmes operate at the district, sub-district, village and hamlet levels, ensuring that caregivers in rural areas who are unable to visit district or sub-districts health facilities would be more likely to access SISCa services in their immediate locale. Typically, SISCa held sessions in government buildings or meeting areas chosen by the community to be in close proximity to the greatest number of potential participants.

Community leaders in Venilale, Baucau, involved in the planning, promotion and implementation of SISCa programmes discussed in detail how SISCa staff would provide services on the days they visited.

In Venillale, Baucau, the SISCa programme visited the village three times per month and the sub-village twice per month, serving an average of 200-300 people per session. All caregivers reported that it took about five minutes' walking time to the SISCa sites, in contrast to the hours they would have to travel by foot or car to reach the nearest health centre.

All mothers interviewed had received between two and four antenatal care check-ups during their most recent pregnancy through the SISCa programme, which took their blood pressure, weight measurements and provided vitamins and health advice on correct maternal nutrition. As one mother in Pante Makasar concluded, '*I was never absent. I always went when I knew the date of check-up. I was never absent until I gave birth*'.

All caregivers reported that all their children older than two months had received vaccinations, either through the SISCa programme or from a static health facility. Caregiver acceptance of child vaccines was widespread and most mothers confirmed their children had received four or five vaccines (depending on the age of the child) and would point to the place on the child's body where the shot was given. Only one mother in Railaco, Ermera, mentioned that her child's first vaccination was delayed due to stock-outs at the clinic, '*When he was born, along with other babies in the clinic that day, we were all sent home because there was no medicine at that time for the first shot after birth*'.

The timing of vaccinations, however, was highly variable across the districts and sub-districts. In Ermera, for example, one mother followed the schedule outlined in her 'baby book', notebooks provided to mothers by health workers containing antenatal advice and space to record vaccinations received. '*I have the schedule, so I just go when it is time*'. Another mother in Ermera explained that she would take her child to the SISCa session held each month and they would administer a vaccination if necessary, whilst a third mother suggested that she only took her child to the clinic when a specific announcement was made (usually during a church service or from a truck with a loudspeaker that would drive around the villages).

In relation to child illness, care-seeking behaviour in Baucau was, in general, characterised by the recognition of symptoms, followed by either treatment at a health facility or treatment with plant medicine for between one and five days until the child's symptoms improved. If the symptoms persisted or progressed or additional symptoms developed, care would be sought from either a local healer or the nearest health facility. If symptoms were identified over a weekend and biomedicine was the preferred first line treatment, caregivers would wait until the clinic re-opened on Monday morning to present their child for treatment.

In Ermera, however, caregivers and health workers both confirmed that attendance with a sick child was often motivated by the health facility distributing the food supplement fortified corn soya blended powder, commonly referred to as 'corn powder' (*batar uut*). Distribution of *batar uut* is supported by the World Food Programme to address moderate acute malnutrition in children between six and 23 months old and malnourished pregnant and lactating women using specific admission criteria based on the mid-upper arm circumference (MUAC). In Ermera, the provision of corn powder was determined the by the nutritional status of children under two, using either their weight or MUAC. In Oecusse, the provision of corn powder was also a motivating factor, but there, its distribution was also based on maternal nutritional need. A mother in Railaco, Emera, whose child had been experiencing symptoms of pneumonia for approximately one week, only attended the health facility for treatment when she heard an announcement that corn powder was available (see Case Study 1 below). A community health worker in the area confirmed that some parents appeared to seek medical attention only if corn powder was provided. As a powerful incentive to attendance, the health worker suggested that food supplements should be distributed to all caregivers, not just those who fit the criteria.

In my opinion, some children when they come every month for the SISCa program or to weigh the babies, those who are given the powder they will be diligent to come. But for those who have a high weight that are not given the powder, the next time supplies are available they don't want to come. If there is something to give, then they ought to give it to everyone, not just the babies who are low weight. Because if you just give

to some and some are not given it due to higher weights, then the next time they [parents] don't want to come because they didn't receive anything before.

In Pante Makasar, Oecusse, the cut-off for children to qualify for food supplements was reported by mothers as five years, rather than two years of age. Across all the districts, mothers who received *batar uut* as a food supplement confirmed that they used it to feed the whole family.

Case study 1 – Mother's experiences of pneumonia and diarrhoea, Ermera

I have a daughter who died from diarrhoea. I don't remember how old she was. She was sitting, almost standing up and trying to walk when she got the diarrhoea and vomiting. When she got the diarrhoea she would eat *sasoro* (porridge) but only very little. She slept all the time. She didn't even cry. She just ate very little.

We took her to Gleno health centre and she was admitted, but after 2 days in the hospital she was sent home. Before we left for home she was given powdered milk and medicine that lasted for two days. One week after we reached home she died.

My youngest daughter is now sick with the diarrhoea and difficulty breathing. She has been sick for one week already. Only today I brought her here to the clinic for treatment. I went to work in the farm one day and when I came back home I saw she had fever, coughing and diarrhoea at the same time. She doesn't play anymore. Her stomach feels like it is squeezing and there is a feeling like something is stuck in your nose and you can't breathe well.

Our house is so far from the clinic, it takes two hours or more carrying the baby. It is difficult to come because sometimes we need to go to the farm and can't carry the baby all the way to the clinic. I came to the clinic today because of an announcement that they were giving the corn powder so I came for the baby to be weighed and for check-up for her to receive some medicines for her sickness. The powder is prepared for the babies below two years. The purpose is for nutrition. It is only provided for children less than two years. Every month, we come when we hear the announcement.

In discussing facility deliveries, caregivers confirmed their primary motivation to give birth at a health facility was their preference for skilled attendance in case 'something went wrong'. This was particularly evident for first time mothers: '*It was knuk foun* (my first baby). *You have no idea, know nothing about the birth so you go to the hospital*' (first-time mother, Gleno, Ermera); '*I had a plan, I wanted her to be born at the hospital* (first-time mother, Ermera Lama). In Bacuau, a mother of a newborn in Vemasse commented, '*I think that it is better to give birth at the hospital because if we give birth at home and if there are some complications during the birth, then there is nobody to help*'. This view was echoed by a mother in Venilae, who concluded, '*We have to give birth at the hospital in order to get help if there is something that happens, such as lack of blood, then we can get a blood donation*'.

Other mothers discussed attending a health facility when their home birth was prolonged or complicated. Comments such as, '*I tried for three days and three nights but was unable to give birth at home*' or '*I tried to deliver at home, but had to go to the clinic because the baby's position was wrong*' were common. The unavailability of a mother's preferred TBA was also a motivating factor, as was advice from health workers to seek attendance.

I decided to give birth in the hospital because when I went into labour the sister of my mother-in-law went away for a traditional ceremony so she was not available to assist me. So I went to the hospital because she who had assisted with my previous births, was not available.

Mother of a newborn, Gleno Hospital

I didn't plan. I didn't think of going to the clinic. I wanted to give birth at home but then the midwife came and did the check-up and she told me that the head of the baby is a little far from the time of delivery, that maybe the head and shoulders are in the wrong position. So she advised I go to the clinic and walk around and do some exercises. And if it still takes time to deliver then she would refer me to Dili hospital…. I knew

that the delivery would be ok for me because the others were born at home and it was ok for them, but at this time the midwife said I needed to follow what they were advising in case something were to happen.
Mother of a newborn, Railaco, Ermera

Female community leaders in Vemasse specified the year 2000 as the turning point in their village for when women started to elect facility-based deliveries rather than home births. One explained,

Around the year 2000 there were some babies who were born with the placenta coming out first and it caused the baby to die. So at the time we were informed by the Alola Foundation (a local NGO working on behalf of women and children) *that all pregnant women should go to the hospital and deliver the babies at the hospital in order to get helped by a midwife.*

Caregivers who first sought health advice and assistance from local religious leaders were frequently referred to health facilities. Their priest would either represent the caregiver, discussing their case directly with health workers, or would be likely to arrange transport to a facility by a church vehicle. A priest in Venilale, Baucau, concluded,

Especially the pregnant women, I ask her, how about your health? Sometimes they explain about their problem, about their situation, their condition, and then I have to write that down and give it to the doctor or nurse. If possible we have to bring them to the clinic…. There is only one [ambulance] here so sometimes it is busy going to Baucau or to another place…so I help them with transportation by providing the car.

Pharmacy

Medicines prescribed by health facilities were provided free of charge at the point of service delivery. It was rare, therefore, that caregivers self-medicated or purchased drugs from public pharmacies. In Ermera district, no participant reported buying medicines, and in Baucau district, the few respondents who had purchased drugs were all based in Vemasse. There, caregivers would buy medicine if they thought the prescription provided by a doctor was ineffective. Medicines were purchased from either the local pharmacy or from a travelling Indonesian drug vendor, primarily selling generic medicines from Indonesia. A mother of a newborn baby in Vemasse explained that when she purchased medicines from the vendor, '*They said the medicine was for diarrhoea, headache, cold, coughing, fever and vitamins. They mixed everything together to pound it, and then they put in a small plastic [bag] and said this is for the children*'. Based upon anecdotal evidence, purchasing medicines from pharmacies or vendors may also be common practice in central Baucau. Due to the study's sampling, however, all the caregivers interviewed in Baucau were admitted to Baucau hospital, and had therefore received medication directly from the hospital. In Oecusse, a caregiver in Passabe reported using Indonesian medicine for her children that her brother had purchased from a travelling vendor. She described the medicine as being 'non-specific' and therefore used to treat children for a range of common illnesses. Another mother in Pante Makasar, Oecusse, bought medicines from a small kiosk close to her house, '*to cope for a while*' before visiting the clinic. She suggested that the kiosk medicine was '*not for fever and coughing, only clinic medicine can be given for those symptoms*'.

Home births, immediate post-partum care and newborn practices

Table 4 – Location of birth and infant mortality by district

District	Place	Age	No. of children	Previous child death	Cause	Place of most recent delivery	Attendant at delivery
Baucau	Vemasse	20	3	No		Hospital	HCW
	Vemasse	28	5	Yes x1	'Family problems'	Home	Relatives
	Vemasse	40	5	Yes x2	From *vistidu* From *vistidu*	Home	Husband
	Venilale	32	6	Yes x2		Home	M-in-L
	Venilale	23	1	No		Hospital	HCW
	Tirilolo	30	1	No		Hospital	HCW
	Wailili	23	3	No		Hospital	HCW
	Triloka	27	3	No		Home	S-in-L
	Laisorulai	24	3	Yes x1	Difficulty breathing[a]	Home	F-in-L
	Oestico	26	3	Yes x1	Lack of nutrition (premature twin)[b]	Home	Husband
Ermera	Railaco	25	3	No		Clinic	HCW
	Railaco	?	5	Yes x2	*Sarampu* (varicella) Diarrhoea[c]	Home	Parents Husband
	Lama	18	1	No		Clinic	HCW
	Lama	18	1	No		Hospital	HCW
	Lama	29	1	No		Hospital	HCW
	Gleno	24	5	Yes x2	Miscarriage Congenital heart defect	Hospital	HCW
	Gleno	34	5	Yes x1	Umbilical cord blood loss	Home	S-in-L
	Gleno	26	4	No		Home	TBA
Oecusse	Pante Makasar	?	8	No		Home	TBA/Nurse
	Pante Makasar	20	1	No		Clinic	HCW
	Pante Makasar	19	1	No		Home	GM
	Passabe	21	1	No		Clinic	HCW
	Passabe	40	5	No		Home	Nurse
	Passabe	27	3	No		Home	Aunt
	Oesilo	35	4	No		Hospital	HCW
	Oesilo	29	4	No		Home	Relatives
	Oesilo	23	3	No		Home	Alone

[a] See Case Study 2
[b] See Case Study 4
[c] See Case Study 1

Location of most recent birth

Of the 27 mothers interviewed in the three districts, 15 (56%) had given birth at home and 12 (44%) had given birth in either a hospital or clinic setting with healthcare staff in attendance. Of those who gave birth at home, 11 had been assisted by family members. In addition to relatives, a mother in Passabe, Oecusse, also had a clinic nurse assist her at home, and a mother in Gleno, Ermera, had a TBA to assist. One mother in Oesilo, Oecusse, delivered alone whilst her husband was looking for transportation to the clinic. Women found it difficult to articulate why they preferred to give birth at home. The most common response was,

'*that's just the way it is done*' or '*this is how my other children were delivered'*. Such statements indicate how Timor custom and birth precedence influence care-seeking behaviour.

Yet Timor-Leste is in a period of transition where the tradition of giving birth at home is being increasingly replaced by facility-based delivery, both elective and in emergency. This was particularly evident in relation to younger women. The average age of the mothers who had delivered their most recent child at home was 29 years, whilst the average age of mothers who had delivered their most recent child at a health facility was 24 years. Amongst the eight first-time mothers interviewed, only one had delivered at home (in Pante Makasar, Oecusse). The group of mothers who reported a recent facility delivery had an average of two children each, whilst the mothers who had delivered at home had an average of four children each. This suggests that younger women are increasingly having facility-based births, and the trend is likely to continue as they have more children.

Post-partum care

The mothers who had delivered at home found it difficult to describe in detail what happened immediately following birth, generally stating that their family had 'taken care' or was 'responsible for that', with little or no elaboration. Those who had delivered at a health facility explained that the baby was placed on the mother's chest immediately after birth and that breastfeeding was quickly initiated. The following statements were commonly iterated: '*After the birth they put the baby on my chest and then they cleaned me, then they weighed the baby and breastfeeding started*' (mother, Vemasse); '*After the baby was born they put her on my chest and then took the baby away to clean her and me. Then after a while they gave the baby to me to breastfeed*' (mother, Baucau); '*After the baby's cord was cut and after the baby was washed then I started breastfeeding*' (mother, Gleno). A mother in Railaco, Ermera concluded,

> *After the baby was born they put the baby on my chest. Then they gave the baby to my mother-in-law to take care of while they cleaned me. After one hour I was told to breastfeed the baby. Then right after that I brought the baby home.*

No mother described difficulties breastfeeding. A few first-time mothers mentioned their confusion over '*why it took so long'* for their milk to come, but this did not deter them from exclusively breastfeeding their child. As one young mother in Ermera Lama explained, '*After birth the baby was crying a lot because I had no breast milk. I took a lot of water and ate a lot of sasora* (porridge) *and after that I was able to start breastfeeding'*. When questioned about the length of time they should exclusively breastfeed for, most mothers responded six months. After that, *sasoro* would be introduced.

Infant mortality

The infant mortality rate presenting in the group of mothers interviewed during the research was 13.2%. While this percentage is higher than the national infant mortality rate of 8.3 % (4.2% in Baucau, 10.2% in Ermera and 9% in Oecusse) (NSD/MoF/ICF 2010), and is a reflection of the selection bias in the research design, it is important to note that past experiences of loss may be highly influential in relation to subsequent care-seeking behaviour.

A number of the conditions that mothers believed had caused their child's death should be highlighted, as they determined care-seeking behaviour for newborns in distress (see Table 4 above for reference). The mother in Venilale, Baucau, who attributed her child's death to 'family problems', had received this diagnosis from a *matan dook* consulted after the death of her 14 month-old son. She was unable to describe any symptoms or illness that the child displayed prior to death, and the family had never taken the child to the hospital. The *matan dook* had informed the mother that the death was a result of a spiritual sickness caused by fighting within the family.

The mother from Ermera who thought her child's death was due to the loss of blood where the umbilical cord was cut, attributed the event to her inexperience, this being her first child. She recounted,

The baby was born at home. I gave birth by myself at two in the morning. There was nobody to help and I could not come to the hospital because it was too far away. The baby was born after two hours. We called someone to come and help cut the cord because I didn't know how to and my mother-in-law didn't know how to cut the cord. We called the sister of my mother-in-law. She came and cut the cord. After that she left, but she didn't tie off the cord so the blood was coming out from the cord, the blood kept on coming out and after one hour the baby passed away.

Narratives relating childhood death are presented in Case Studies throughout this report. Death due to diarrhoea is presented in Case Study 1, from 'difficulty breathing' in Case Study 2 (below) and from 'lack of nutrition' in Case Study 4.

Case study 2 – Delayed treatment after home birth, Baucau

My second child died because of difficulty breathing when he was four months old. He was just crying and crying and then he couldn't breathe and then he died. It felt like he was breathing, but his voice wouldn't come out. We didn't go to the hospital.

The nurses say that when the time comes to deliver then you should come to the clinic, but we live far away and my father-in-law can help during the delivery. I recently gave birth to my third child at home with my father-in-law assisting. There were no complications during the delivery, but after she was born she didn't take the breast. For two weeks she wouldn't take the breast. She couldn't suck and was breathing so slow out of her nose. I tried dropping the milk into her mouth and then I gave a formula named SGM that a relative gave me. I put a spoon in the formula and tried to give her that, but she wouldn't take it either. There were some sores inside her mouth. My father-in-law went to a traditional healer and he was told to give goat's milk to the baby, we tried but it didn't help. We tried to give the goat's milk for one day. After that, my father-in-law decided that I would bring the baby to the hospital. This was about two weeks after I gave birth.

I took public transportation to get to Baucau Hospital, just the baby and me. When we arrived at the hospital they gave her *soru* [intravenous fluid] and oxygen and they removed the dirty blood from her throat. There was something that was stuck in her throat, making it hard for her to breathe and to cry and to suck milk. We didn't know. The nurse said she had difficulty breathing because of the dirty blood in her throat. Her weight was very low, so they put her in the machine [incubator]. They gave her breast milk mixed with formula using a tube and asked me to breastfeed, but she still couldn't suck so they had to give her milk through the tube.

Newborn care practices

Mothers across all districts discussed the common Timorese custom *tur ahi*, literally 'sitting fire'. This practice necessitates both mother and newborn to be sequestered inside the home for a period of time, from several weeks to three months, with an open fire and often closed windows and doors, '*in order to make the room warm*'. Caregivers perceived the fire to be beneficial to mother and child for several reasons: to help the mother produce more breast milk; to heat the mother's breast prior to feeding; to prevent swollen breasts; to prevent future sickness in the baby; and to 'strengthen a mothers back' so that she would not have pregnancies close together (ie. to help with birth spacing).

A mother in Venilale whose child had pneumonia and diarrhoea explained that her mother-in-law and sister assisted her during and after the delivery, '*They put a fire on to heat me and told me to drink a lot of warm water and eat a lot in the evening to have enough breast milk*'. Another mother in Ermera Lama was given similar advice by her relatives, '*I was advised that after the baby was born to stay close to the fire, not too close and not too big of a fire but something to stay warm, for both me and the baby to feel warm. And to drink a lot of warm water'*.

Several TBAs interviewed described *tur ahi* and confirmed their perception that it was a beneficial practice. A TBA in Venilale, Baucau, explained,

> *Our ancestors believe that when the baby is born there should be near the fire otherwise the baby will not be strong, and mothers' breast milk will be cold and to avoid a mother having swollen breasts. So that's why people put fire on.*

This sentiment was echoed by another TBA in Passabe, Oecusse, who concluded,

> *If the woman gives birth at home then she has to be inside the house during three months then after that she and baby can be brought out of the house. It's different with women who give birth at clinic and takes modern medicine, but even after delivery at clinic, when they go home, the woman and baby should still stay inside.*

In contrast, one TBA in Venilale, Baucau, thought that the practice of *tur ahi* should not continue as it was dangerous for a newborn to inhale smoke from the fire. He explained, '*Now we advise mothers to drink plenty of hot water instead of putting on the fire and sitting or sleeping next to it. Smoke from the fire can cause difficulty breathing and a running nose for the baby and the mother*'. This TBA had stopped promoting *tur ahi* in 2009 after an announcement by the village chief and SISCa doctor who described risks associated with the practice and its potential harm to mother and baby.

In their focus group discussion, health professionals at the clinic in Ermera Lama described *tur ahi* as contributing to newborn pneumonia in their area.

> Midwife: *When women give birth they don't want to go to the hospitals or health centres, they just give birth at home. They use the fire. The mother and baby are sleeping close to the fire. Their beds are close to the fire and the smoke from the fire is going in to the babies, going inside the nose of the babies and causing pneumonia*.
>
> Doctor: *The purpose of the fire is to help the mother's breast milk and for the baby not to feel cold. To keep the temperature balanced. In some areas here people used to explain that the baby will not have any sickness in the future because they have made the baby feel hot and feel in balance when they are a newborn… I explained to this one patient that the fire was causing this child's pneumonia but the patient said to me that this is our culture, we have to do this. If not, then in the future children will get sick*.
>
> Midwife: *Timorese have this culture. What I have seen here in Ermera is this practice but I think they have this in other parts of Timor because we have cultural traditions that are related to each other, but this is our experience here in Ermera*.
>
> Chief of Health Centre: *People are already reducing using the fire but those who are living in the rural areas, far from the health centres, with no roads accessible to transportation, of course they still do these things*.
>
> Midwife: *Some women know already that they should not stay close to the fire because they have already got some information that staying close to the fire with the baby is dangerous, but the father-in-law or the mother-in-law or the husband is already preparing the fire and so she feels obliged to go and use the fire. When she is alone she must follow the wishes of her family, their instructions. She has to be there with the fir*e.

Other newborn practices that were discussed included covering the fontanelle (*batoton*) with mashed candlenuts and not washing the mixture off for between eight and nine months or until the soft spot had disappeared. Some mothers also suggested that newborns should be bathed three or more times a day. A doctor in Ermera Lama countered this, explaining, '*They give a bath to the baby three times, or sometimes more, a day and it makes the baby feel cold. Three times a day for a newborn for example. This can cause pneumonia to babies*'. Even if they did not practise *tur ahi*, many mothers would have a period of

confinement for at least 40 days. In relation to this practice, the chief of the health centre in Ermera Lama concluded,

During 40 days they don't let the mother bring the baby out from the house, some sitting close to the fire. The baby has lack of vitamin D because of lack of sunshine. We call this 'fase matan', it means after 40 days they will have a cultural ceremony and after this ceremony you are allowed to bring your baby outside. This practice of staying 40 days inside the house also prevents the baby from receiving the first vaccine that should be received two weeks after birth. The polio vaccine should be received, but they cannot do this due to this taboo of keeping the baby inside the house for 40 days.

Decision-making and agency to act

As illustrated by several of the quotes included above, the influence of family and relatives was an important factor in care-seeking behaviour in Timor-Leste. Seeking treatment, both local and biomedical, was most often a familial decision, with fathers and mothers-in-law being frequently deferred to. Across all three districts, it was common that the attending parent of a hospitalised child was the father, whilst the mother remained at home to care for the rest of the family.

Agency to act was more restricted for pregnant women and those who had recently delivered, particularly if they lived in close proximity to their husband's family. When discussing the location of birth, health workers in Ermera remarked on the inability of expectant women to follow their advice, given '*many many times*' to deliver at the health clinic, due to their family's preference for a home birth. A midwife in Ermera Lama clinic concluded,

When a woman says she wants to do something different, her family will say she is listening to the instructions of other men, so it is like a bad impression on you. So whether you like it or not, she has to follow what they [the family] say.

The mother of a hospitalised newborn in Baucau Hospital related the control that her father-in-law exerted in decision-making and regarding health practices. It was her father-in-law who delivered her child, suggested she feed goat milk to the baby since he was not suckling properly, and who eventually gave his consent for the newborn to be taken to hospital two weeks after birth.

A doctor in Ermera discussed familial influence in relation to the distance mothers lived from a health centre. He concluded,

For those who are giving birth at home, it is usually those who are living far from the health centres. They don't prepare, they don't make any plans where they will give birth… When the time comes the woman must follow what her family says, what her mother-in-law or father-in-law is telling her to do. She must follow this.

Other health workers discussed the fact that husbands forbid their wives from using family planning methods, and women were therefore unable to control the number or timing of their pregnancies. A TBA in Gleno, Ermera explained,

Of course husbands, they like to have more children, and some women… they keep on having babies. Every time the mothers are always carrying the baby because one is coming right after another so they have no chance to do anything. It is worse if the husband is already jobless and he just wants to walk around here and there doing nothing. That is the worst one.

Mother and son, Baucau Hospital, Baucau Distict

Barriers to care seeking and treatment

Barriers to care seeking and treatment uptake were analysed according to five key themes: financial barriers; access barriers; health facility deterrents; knowledge and information barriers; and socio-cultural barriers including gender. This chapter seeks to highlight the key issues identified for each barrier.

Financial barriers

Table 5 – One-way cost of transport to attend health facility

Mother's residence	Purpose of visit	Transportation public / private	Cost (USD)	Monthly income (USD)
Baucau	Delivery	Private car	5	0
Baucau	Delivery	Public bus	1	0
Ermera	Pneumonia	Public bus	1	20-40
Ermera	Pneumonia	Public bus	9	50
Oecusse	Diarrhoea	Public bus	1	0
Oecusse	Delivery	Private motorbike (*ojek*)	1	50

The most significant financial barrier enumerated by caregivers was the cost of transport to access a health facility. Table 5 presents the costs incurred by participants who had recently attended a health facility, either due to child illness or for delivery. The monthly income listed is the whole family's monthly income range and is highly variable depending upon the season (for the sale of crops such as coffee) and employment circumstances of the husband or household head. All mothers interviewed described the mode of transport and the required out-of-pocket expense to be major considerations prior to seeking services at a health facility. A mother whose child was hospitalised in Baucau due to pneumonia and diarrhoea explained, '*I think the clinic services are good for the baby, but the problem is the transportation. Sometimes we really need to go but there is no car at the clinic so we have to use microlet* [public transportation]'. Health workers and community leaders echoed these concerns. A midwife in Baucau confirmed, '*No transportation and a lack of money to pay transportation fees in order to bring the child to the hospital is a big concern*', and a nurse added, '*People's economy is low so they don't have enough money to pay for transportation*. Despite the fact that services and medicines were provided free of charge, the financial barrier associated with accessing health facilities was problematic. A priest in Vemasse concluded, '*First, the challenge is the distance, transport and money, because it is hard for people to afford but they try hard to com*e'.

Access barriers

Caregivers who could not afford transport, or who lived in remote rural areas where transport was unavailable, often had to walk long distances carrying their sick child. A mother in Baucau hospital whose child had pneumonia described, '*I just carried the baby from my house to the local clinic, for two hours. I had no money and there was also no transport. When we reached the clinic, then they called for the ambulance to take us to the hospital*'. Transfer by ambulance was free, but the limited number of vehicles was insufficient to cover their target areas effectively. In addition, many villages had restricted access, particularly those at high altitude where the paths were rocky and often impassable for vehicles, and this further prohibited the use of ambulances.

In Oecusse, there were four ambulances in the district, one per sub-district, to cover the 64,000 residents. Health workers in Gleno confirmed there was one ambulance for each of the seven sub-districts in Ermera, to service a population of over 117,000, and as a nurse asked, '*What happens if two, three, four or five*

people in each sub-district get sick at the same time? There is only one ambulance for them all'. Similarly, community leaders in Venilale confirmed that the six sub-districts in Baucau had one ambulance each, to service a population of over 111,000. A doctor added that as Baucau hospital was the referral centre for all the sub-district clinics, it was supposed to have three ambulances, but at the time of the study, two were broken and out of service. This was why community and religious leaders were often called upon to provide their private vehicles to transport patients to hospital (discussed above). A mother in Ermera whose child was hospitalised with pneumonia explained,

We live far away from the hospital and far away from the main road. To get her [the daughter] to the hospital we had to wait for my young brother to arrive. He had gone to Dili to register for his study. We had to wait several days for him to return and he came only yesterday. Only yesterday he could bring us to the hospital on the motorbike… If he didn't come back by yesterday, then I was going to carry her and walk slowly-by-slowly to reach the hospital because she would not eat anything.

Because of the limited coverage of ambulances, participants suggested that even in an emergency situation it may be better to travel to the hospital independently rather than wait for an ambulance. As a nurse in Vemasee concluded,

Recently there was a pregnant lady who came, I told the priest to use his phone to call the ambulance…At the time the ambulance was on the way to Dili, so there was no ambulance available. That is why I had to go to the priest to ask for his car in order to take the pregnant woman to Baucau.

The father of a child hospitalised for pneumonia at Gleno, Ermera, confirmed,

The most difficult thing for us is that we are living far away from this health centre. We don't have transport, we don't have a car when children get sick and we want to bring them right away to the hospital. Now we have an ambulance and the ambulance can help and if there is space on the public transportation we can ride, but sometimes there is no public transportation and no ambulance available and then we have to walk. When we have to walk it can take four hours for us to reach health services.

For caregivers who had to walk to their closest health centre, the most common length of time ranged from two to four hours. Unable to leave other young children at home, mothers were frequently accompanied by the sick child's siblings, and this could significantly add time to the journey. Walking was seen to be particularly problematic during the raining season, when road access was further restricted, and in Ermera, caregivers stressed that the rain was often '*too hard for them to walk the distance'*.

In relation to child birth, a mother in Vemasse, Baucau noted that '*it was better to go to the health centre to give birth*' but asked how women most in need of the services, '*those mothers who don't have enough strength to deliver*' were meant to get there. The mother of a newborn in Gleno echoed this concern, stressing that accessing healthcare was often a matter of life and death for Ermera residents.

The mothers who are going to give birth, they want to give birth in the hospital but it is so far away and too far to call the nurses or midwives who also live far away. It is already time to give birth, so sometimes they come and try to reach the hospital but they die along the way. Death caused by bleeding… Also, the mothers or children when they get sick they really need the assistance of the midwives and nurses but because of the distance it is not possible. They come, but when they reach the hospital it is already too late and their life has already been taken. It is too late to help them.

Similarly, in Railaco, a community health volunteer confirmed, '*For those place where the car cannot reach, where there is no road, people will just stay at home until they die. Or by the time the nurses reach their home, they must already say goodbye to the baby*'. Instead of describing the need for an ambulance, a mother in Ermera Lama suggested that a hearse was more appropriate, '*We need a kareta tula mate*

[mortuary vehicle]*, the car used to bring the people from Ermera who died in the hospital back home. We need the car to carry the dead bodies back home*'.

TBAs in Oecusse recounted that they had to walk '*from the morning to evening'* in order to reach labouring women who lived in remote mountainous areas. A TBA in Venilale suggested that the inherent challenges of distance, time and accessibility were further compounded when emergencies occurred at night (see Case Study 3).

In my experience, there were two mothers who died because the placenta didn't come out after the baby was born. One happened in Vemasse and the other one was here in Osowake. It was just because they were living far away, something like both babies were born around 1am and they came to call me after several hours when no ambulance was available, so it was too late. The mothers died before I arrived.

Case study 3 – Mother of two-week old, Oecusse

When I was pregnant, I went to the clinic for a check-up and they told me that I needed to give birth at the clinic. So I had a plan to give birth there. I had a plan with all three of my children to give birth at the clinic, but all of my children have been born at home.

With this baby, I tried to go to the clinic to give birth but it was night time when the water broke. I sent my husband to get an *ojek* [hired motorbike] to take me to the clinic, but the baby came before he got back. It takes about two hours to walk to the clinic and about one hour by motorbike. So I delivered alone in my house. I didn't lift the baby after he came out, I just left him on the floor between my legs waiting on my family to come. After he came out, my uncle arrived and cut the cord with a knife and then my aunt came to wash the baby. Later my husband went to the clinic to tell them that I had given birth. One week ago someone from the clinic came to weigh the baby at the village office.

An additional burden raised by participants was the need for hospitalised children and labouring women to be accompanied by other family members. This could put an added strain on the logistics of accessing healthcare, as relatives were needed to support the household in the village, but also the patient in the hospital, both socially and economically. As a midwife in Baucau Hospital concluded, '*If they go to the health centre they also need family they can stay with whilst they are doing the treatment… If they don't have any family that live close by to the clinic, maybe they will not come*'.

Caregivers who lived in close proximity to a health facility and were not restricted by access barriers, were keen to emphasise which of their neighbouring areas were the least accessible and therefore posed the greatest challenges to the health of mothers and children. Baucau residents listed Waibobo and Waimori Tula, and Ermera residents listed Urahou, Likesi, Fatubessi and Lisapat as the most difficult to access. These areas often required patients to be carried from the village in chairs or on homemade stretchers until they reached an accessible road where transport could be sought.

A representative from Health Alliance International, an NGO that supported the SISCa programme, emphasised that the most challenging aspect of their work was helping SISCa staff to access difficult to reach populations.

The most difficult thing we do is the support we provide to SISCa. This is because of lack of transportation. We cover five districts and some babies are just dying at home because the mothers are late arriving to the hospital. They are late coming because of the bad roads.

Health facility deterrents

Health facility deterrents are reviewed as three interrelated areas: limited clinic working hours and lack of health staff; attitude of health professionals; and lack of medical equipment, drugs and facilities. While these issues may not prevent or preclude attendance at health facilities per se, they were detrimental to positive and timely care seeking and may have negatively affected the quality of service provided.

Limited clinic working hours and lack of health staff

Caregivers found the operational hours of health facilities to be restrictive, in terms of limited clinic hours Monday to Friday, and the fact that health facilities were closed over weekends. A mother in Baucau described her desire to give birth at the clinic, but her first and third child were both born at home, during the night, when the clinic was closed. She was able to deliver her second child at the clinic because she gave birth in the afternoon. A first-time mother in Ermera Lama recalled that her water broke ('*the hot water came out*') at 3am, and because she was fearful to deliver at home as it was her first child, she immediately began walking to the clinic and arrived at 4am. The building was closed and she had to wait for a further two hours until a health worker arrived to provide assistance. Caregivers had experienced similar frustrations in relation to child illness. Several parents commented that their child's symptoms had started at the weekend, but they were not able to access care until Monday morning, '*Because people don't work on Saturdays and Sunda*ys*'.* A mother interviewed in Baucau Hospital explained that she had first noticed her son's symptoms (fever and coughing) on a Friday afternoon, and when they presented at the local clinic on Monday morning were immediately referred to Baucau Hospital due to the severity of his condition. Parents in Pante Makasar discussed using traditional medicine when the clinic was closed, or if there was an emergency, being forced to contact the clinic's doctor or nurse at their home, '*but only on a Saturday or Sunday*'.

A notable exception was the clinic in Passabe, where, although being closed at the weekends, clinic staff would still treat emergencies. One mother described how her waters broke at 3am on Sunday morning, and her husband walked to the clinic, found the doctor, sent a car to collect his wife, and she was able to deliver at the clinic that afternoon. Another mother, whose child had experienced respiratory distress, was not deterred from going to the clinic when she first noticed the symptoms on Sunday morning. She explained, '*I brought him to clinic because the doctor stays close to the clinic even on a Saturday and Sunday… They take good care of me, when we send somebody to ask for help, they really help*'.

According to the times caregivers reported, the average waiting time at clinics across all three districts was between two and three hours, if caregivers arrived at 8am or earlier. If they arrived later, it was harder to secure an appointment and the waiting time would likely be longer. One mother in Venilale confirmed that she always walked to the clinic very early in the morning because she knew '*there would be a line of people waiting and the clinic staff usually left at lunchtime*'.

Caregivers also emphasised that there was a lack of health workers and that staff at hospitals were often overworked and too busy to properly attend to their patients. The mother described above, whose son was referred to Baucau Hospital with pneumonia, recounted that the nurse at the local clinic who made the referral inserted an intravenous drip into the child's arm before the ambulance arrived, as she was concerned that the hospital staff in Baucau would be too busy to perform the task on his arrival. According to the mother's narrative, the nurse's concern was justified,

> *I went to the clinic in Triloka where he was examined by the nurse. Because his temperature was so high they put on a compress and put a drip in and gave him Paracetamol. The doctor at the clinic said that it is better they put a drip in because nurses at the hospital might be busy with many patients… After arriving here at the emergency room, they asked where we are from, and then they showed a place for the baby to go but they didn't do anything else because there were too many patients.*

A mother in Gleno, Ermera, explained that, at the time of interview, her daughter had been admitted to the hospital for five days, yet they were still waiting for the qualified member of staff to draw her blood.

> *During the first check-up I was also told that there is a nurse here, one nurse who can draw the blood, but the nurse is gone somewhere for training. We are still waiting for the nurse to come back to take the blood… He's the only one in charge of taking the blood, the rest of the staff cannot do it that is why we are waiting for him.*

Attitude of health professionals

Caregivers in all three districts described the negative attitudes of hospital doctors and nurses. This was particularly noticeable in Baucau, where one mother who was attending her child hospitalised with pneumonia and diarrhoea commented, 'Some nurses, especially females, sometimes get angry when they hear babies crying. They shout at the mothers and are impolite and rude'.

Another mother, with a child hospitalised in Baucau with diarrhoea, described the fear she felt when the doctor told her, soon after she arrived, that there was nothing he could do for the child because she had brought her baby to the hospital too late and should instead go see a *matan dook*. As discussed above, *matan dook* can be consulted at two distinct points in a child's illness: before treatment at a health facility in order to enable the biomedicine to work; and/or after biomedical treatment has been sought, but was ineffective. In suggesting that she should see a *matan dook*, despite having sought care for her child at a health facility, the mother interpreted the doctor's statement to mean that the child was in critical condition. She explained,

> *When the baby was checked by the doctor he asked, 'why do you only now bring the child, why you didn't bring him earlier to the hospital?' The doctor put a drip in and gave oxygen and then was telling me that the heartbeat is running so slow already. He said the baby was in a hopeless situation and that I needed to fix something wrong in my family.*

This mother spoke of the guilt the doctor had made her feel, but had decided to keep the child in hospital, and at the time of the interview the baby had just been released from the intensive care unit due to improvements in his condition.

Caregivers also discussed their mistrust of hospital personnel. A father in Gleno, Ermera, expressed his frustration, '*This is the third time we have been admitted to the hospital. I am confused and angry. I am wondering why my child has been admitted three times for the same sickness? I don't know why she is not getting bett*er'. Distrust was also expressed by caregivers in relation to the frequency and inconvenience of stock-outs, discussed below.

Lack of medical equipment, drugs and facilities

Although medicines were supposed to be provided free of charge at hospitals and clinics in Timor-Leste, and the need to pay for drugs was not raised as a financial barrier to seeking care, there were instances when hospital stock-outs required caregivers to self-fund medication. A mother in Baucau hospital explained that she had overheard conversations between several mothers on the paediatric ward who had been asked to pay for expensive medicines to treat their child, '*I heard yesterday that the nurses told the patients to go and buy medicine outside where one bottle of medicine cost 9 dollars. The nurses said that there are no more medicines here*'. This mother had been informed by her referral clinic that it was likely she would be asked to purchase the medicine required to treat her child's pneumonia, but a friend who was a nurse was able to provide her with the appropriate medicines to take with her to Baucau hospital. She concluded,

I was lucky because I brought two bottles of medicines from the clinic. I was told by the nurse to bring the medicine from there, just in case there was no medicine at the hospital… There are mothers here from Viqueque who said that I am lucky because I have my own medicine. They said that they had been here for two weeks but there was no medicine for their babies so they had to buy somewhere else… I was told that there were interviews here today and I hoped that it could be me to be interviewed so I could tell you about this'.

Stock-outs at clinics and hospitals were also common in Ermera. Mothers frequently described arriving at the health facility with an ill child, and being told to come back at a later date, usually the following week, to see if new drug supplies had arrived. A mother in Gleno stated, '*During the time my first child had fever and a running nose, they told me to come back on the next Monday or after two or three days to get the medicine*'. Similarly, a mother in Railaco explained,

When one of my children got fever and coughing and we went to the clinic, we were told there was no more medicines, that they had to make a request to Dili for the medicines. So we were told to come back for another check-up when the medicine was available.

This mother also confirmed that her newborn baby and two others did not receive their first vaccinations whilst in hospital after delivery due to the lack of hospital supplies. Caregivers in Oecusse related similar experiences. A father attending his hospitalised child in Gleno, Ermera, described,

On the other side of the room this morning the doctors said a baby girl needed to go to Dili Hospital. The parents wanted to refuse, they didn't want to go to Dili, but the doctor said we need to give you a referral to Dili because we don't have the medicine here for your child's sickness.

Interestingly, participants did not articulate the need for onwards referral as a barrier to care-seeking, although it presumably required additional resources (both financial and non-financial). In some cases, however, health workers arranged for medicines to be purchased on behalf of the caregiver. A mother in Oesilo, Oeucusse, explained, '*There was a time recently when I went for medicine for my child and the doctor said that there is no medicine, but we will go to Oecusse to get it for you*'.

A mother in Railaco, Ermera, who lived a two-hour walk from the local clinic, emphasised the commonality of drug stock-outs. She explained that the potential lack of medicine influenced her decision about whether or not to take her children to the clinic when they were ill, and it also negatively affected her perception of the health workers.

Sometimes when we come here, after the check-up they say there is no medicine and you need to come back later, and then when we come back later they still say there is no medicine and to come back in the next few days or next weeks. That is telling us lies… My house is so far from here, sometimes it takes more than two hours to get here with my children. When we come and then there is no medicine, they ask us to go home and then come back. I feel like they are telling lies.

There were several occasions in which caregivers had sought treatment for the child's diarrhoea and encountering a lack of medicine at the health facility had been turned away, without being given any advice or possible alternative. Health workers in Ermera Lama confirmed that they informed parents how to make a simple ORS at home (discussed above) and emphasised that this was a common coping mechanism to counter the clinics' stock-outs. In addition to limited and unreliable supplies of drugs, health workers described their need for additional equipment. Staff at Baucau hospital, for example, suggested they needed basic first aid equipment.

Mothers in all three districts emphasised the lack of space and privacy at both clinics and hospitals. A recently delivered mother in Railaco, Ermera, confirmed that the lack of privacy had contributed to her

anxiety about giving birth at the clinic at the behest of the midwife. She believed that other women in the area shared her opinion and that it deterred their attendance.

Women prefer to give birth at home because the clinic has no separate facilities for maternity. No separate spaces for women to deliver. In my case, I delivered at the clinic because the midwife said I needed to go for the services, but they don't have maternity facilities so for some who have delivered there it is by force from the midwife. Women do not prefer to give birth there.

In their focus group discussion, representatives from Health Alliance International, Childfund and CARE highlighted the lack of privacy for labouring mothers as a significant issue, particularly for women who came to the health clinics from rural areas or those living in poverty. As one CARE member of staff explained,

Some women say they don't want to deliver at a health facility because they are shy to be in a public place, with many people, with their old clothes. They don't have new clothes to put on after the baby's birth and so they are shy to show this to other people.

Other stakeholders anticipated that limited running water in the washrooms and a lack of en suite facilities would be detrimental factors raised by mothers as reasons not to attend health facilities. These concerns were not reflected in the research data, however, and all clinics visited during fieldwork had running water in the toilet facilities.

Knowledge and information barriers

In relation to child illness, it was striking that whilst caregivers admitted having low levels of knowledge, particularly regarding prevention, mothers found it very difficult to articulate why their knowledge was lacking, what more they wanted or needed to know, and where knowledge about their child's health should come from. Although caregivers could easily recite the medicines that their children had previously been prescribed (eg. Paracetamol for fever, Amoxicillin for coughs), they had rarely been given any health advice by a health professional at a clinic or hospital. Despite this, they did not often perceive their lack of health education to be a result of health workers neglecting to provide sufficient information, rather they appeared resigned to not knowing. There were a few notable exceptions, such as the father whose daughter was hospitalised for pneumonia in Gleno, Ermera, and whose frustration at a lack of information had developed into mistrust of the health staff (presented above). More commonly, however, caregivers stated the lack of communication by doctors as matter-of-fact and did not perceive it to be a barrier. When asked if they had received any information about their child's condition or during their check up, the following quotes from caregivers across all three districts were representative.

They didn't say anything. They just checked the baby and said that I just wait. (Mother, Venilale, Baucau).

They didn't say anything about the x-ray result, what sickness that the baby has. And it was the same with blood result, they didn't tell anything. I haven't got the x-ray photo up to now, maybe it will be given later, I don't know. (Mother, Baucau Hospital)

They just told me that the child is in this condition and to give this medicine, but they didn't say anything more. (Mother, Baucau Hospital)

The Cuban doctor who checked her out said she needed oxygen and that I should just wait. I am just waiting for the doctors to tell me something. (Father, Gleno Hospital, Ermera)

The doctor did not say anything, just gave instruction to give the medicine. *No more information was given*. (Mother, Passabe, Oecusse).

One instruction that health workers commonly gave to caregivers was keep their child away from dirty and dusty environments. Caregivers stressed that due to their living conditions (often in houses with mud floors, close to dusty unpaved roads) it would be impossible to follow these directions.

Given the high levels of morbidity and mortality amongst the study's participants, it was surprising that caregivers displayed such a low demand for knowledge and information. This has implications regarding how health education and communication for development should be designed and targeted.

Expectant and recently delivered mothers are excluded from the above analysis as they described frequent interactions with SISCa and other NGO staff on topics including: childhood vaccinations; proper maternal nutrition; the importance of antenatal care and breastfeeding; the need to deliver at a health facility; and to keep their home environment clean.

In Ermera, community members suggested that *Promotor Saude Familia* (PSFs) were a potential source of health information. In their focus group, NGO representatives expressed concerns about the role of PSFs. Whilst they agreed that, in principle, using family health promoters from the local community was theoretically sound, they also suggested that the close proximity of the PSFs to the communities in which they worked may have hindered rather than advanced positive health messages. One representative explained,

> *It depends on the background of the individual PSF. Some didn't go to school. They try to mobilise the community but they also live in the community so if the community sees them screwing around at night and then coming and telling them how they need to act during the day, why would the community listen to them? If the PSFs are not practicing the healthy behaviour that they are asking the community to practice, why would anyone listen to them? Some are not a good role model.*

Socio-cultural and gender barriers

Although caregivers did not highlight socio-cultural barriers to care-seeking, other participants (including health workers, religious and community leaders) identified three main issues: the persistence of cultural traditions; familial preferences for many children (often to the detriment of women's overall health status); and gendered time constraints.

Cultural traditions

The persistence of cultural traditions influencing health-seeking behaviour was explained by a volunteer health worker in Railaco, Ermera, as unwillingness on the part of caregivers to give up certain practices.

> *For the health information given to families, it's not that they don't understand, it's that they don't want to understand. Can you get the difference? Some people will pretend not to understand the information that was given.*

In Baucau, religious leaders described some people's preference for traditional practices as a consequence of their fear of modern medicine and the low level of education of some caregivers. A priest in Venilale explained, '*They are not yet ready to accept the modern, the doctors. They are afraid*', and a priest in Vemasse concluded, '*If people have enough education then they are aware to go to hospital, but for uneducated people they tend to believe in magic*'.

Health workers in Baucau appeared to accept that people continued to visit different traditional healers, including *matan dook*, because health centres were not easily accessible. In their focus group discussion,

however, community leaders in the district presented a different interpretation of why cultural practices and the familial advice given by *matan dooks* persisted.

Parliamentary member: *The reason is that, before when there were no doctors, our ancestors lived with this kind of thing. In Portuguese times there was only one nurse, but before that our ancestors lived with illness so when they were sick they could just find roots or leaves and boiled them and it was cured. There was a bit of change during Indonesian times where doctors and midwives were available, diminishing the practice of going to traditional healers. Up until now we are still practising it, but it is more related to our culture. For example if we go to the doctors and we are still sick then we have to find out culturally what is the cause by going to matan dook… they might say that maybe you disrespect your parents, or one of your relatives died somewhere and you don't know where the dead body is.*

Sub-village chief: *What the matan dook does is more on spiritual level that can't be seen or touched so that is our culture in Timor. Culture and medicine are always related to each other.*

Family planning

All the participants in the study were Catholic and in terms of family planning, were influenced by the 'natural method' promoted by the Church, sometimes referred to as the 'Billings Method'. This requires women to monitor their fertility based on the level of discharge of vaginal mucus, with increased discharge suggesting ovulation. Although both religious leaders and health workers, including TBAs emphasised the need for family planning, it remains a sensitive issue in Timor-Leste. As a priest in Venilale, Baucau explained,

For the church, it's difficult to tell them about how many children they should have because the doctrine forbids to tell how many children you can have. Sometimes we just tell them to be careful and to space their children, but don't tell them only to have one child or two children. Just to space children depending on their personal economy.

Apart from Catholic teachings, the priest was also alluding to family planning campaigns from the mid-1970s to the mid-1990s. During this period of Indonesian rule, the government's slogan was 'two children are enough'. The campaigns were perceived to be a form of unwanted social control to decrease the Timorese population, and negative perceptions of Indonesian family planning programmes still linger.

Some health workers associated the lack of responsible family planning with limited educational opportunities. A midwife in Ermera Lama concluded,

Some people who marry have no education at all, so they have no access to health education and do not know how to plan for healthcare when women have to give birth. So we can say that the lack of health education on the part of these people makes it hard for them to plan for births. Up to now in Timor, family health planning is still lacking due to people's education level.

A TBA in Ermera described that she would often have to assist the same woman with multiple deliveries, despite trying to tell grand-multipara mothers that to have successive pregnancies year-after-year was dangerous to their health and the health of the babies. She explained,

Now if the women take the birth control, at least they can space their babies after two or three years apart. But for others who do not do this after another six months they are pregnant with another baby. Like a water drum filling up again and again. After six months or one year another baby filling up the drum again… So people will always come to me, there will always be babies. I used to tell them you need to have another baby after two or three years not six months, but they say they want to have more babies and then they have lack of strength and feel weak… Some people they understand and some people they were able to do

the family planning, but some of their husbands forbid them to do this. I keep on telling them so that they will start to understand what I am saying: take the family planning and wait to have another baby.

Sometimes a woman would not recognise her pregnancy until the fifth, sixth or even seventh month because she was still breastfeeding her previous child. This delayed seeking antenatal care, not due to an unwillingness to attend or lack of access, particularly where SISCa programmes were operating, but because she was not cognisant of her condition. As one mother in Vemasse confirmed, '*I started antenatal care with my first child when I was three months pregnant but not with the last baby until I was at 6 months, because I was still breastfeeding and didn't notice I was pregnant*'.

Gender as a socio-cultural constraint

The impact of gender and the gendered roles in Timorese society is a backdrop to many of the discourses on maternal and child health. As discussed above, women have limited decision-making capacity, shoulder significant workloads (particularly in agricultural families) and lack educational and employment opportunities.

Case study 4 – Mother of newborn twins, Baucau

I gave birth to two babies. I didn't know I had two inside, even the nurses they didn't know. Every month I went to the health post in Oestiku to the place for the SISCa programme. I went to that place for treatment and for check-up every month until they were born.

I told the SISCa staff that I couldn't eat any other food, just *sasoro* (porridge), but they just gave me vitamins, they didn't say anything else to me. Since my fourth month of pregnancy, I could hardly eat food because I was vomiting, and feeling short of breath, and like I had no appetite. I just ate the *sasoro* until the babies were born.

The babies were born early, during my eighth month of pregnancy. My older son was born early too, during my eighth month. I don't know why all of my children are born early. A few days after the twins were born I got sick, it was difficult for me to breathe and I had a lot of coughing. I couldn't breastfeed them anymore so I started to give the formula SGM. On the fifth day after birth my husband called the ambulance because I felt so weak. We were brought to Baucau Hospital.

When we came to the hospital they separated me from the babies. It was explained that they were too small and so needed to go into the machine [incubator]. They went to the children's ward and I was put in a different area of Baucau Hospital. My husband stayed with the babies while I was receiving treatment. They gave me *soru* [intravenous fluids] and oxygen for one week and medicine to take. I was told that I got sick because I was working too hard when I was pregnant.

Before I was released from the hospital one of the twins died. After one week in the hospital he died. The doctors came and took his blood, and after they removed his blood and the tape on the arm the baby passed away. I've been in the hospital now for three weeks with the other baby.

As follow up to the mother's narrative, the case was discussed further with a nurse in the children's ward at Baucau Hospital. The nurse described how both the babies were 'very small' when they arrived at the hospital, weighing less than two kilos each. The mother had presented late to the hospital and treatment had been delayed because she had become so ill with pneumonia that she could no longer breastfeed. The nurse explained,

Due to our overloaded work schedules, it was the responsibility of the father to feed the children while their mother was in another wing of the hospital. The father said that he was giving the babies formula, but I suspect that the twin boy who died was not receiving this nutrition. He died from lack of nutrition.

There must have been something blocking his throat preventing him from receiving the formula and causing the baby to aspirate into the throat. Only when this happened, when the baby started to vomit, did the father come and get us. When I checked the baby, the skin was very white like death. We tried to put an IV in the baby's arm, but it was too late. The child was already dead.

The deleterious health effects on women are cumulative, with poor maternal nutrition and bodily stress directly contributing to the increased likelihood of obstetric complications and decreased newborn health outcomes. When discussing these issues, a nun of the Canocian Community working in Baucau explained,

Timorese people pay more importance to their work so, for pregnant mothers, sometimes they don't think about their condition and the baby in their womb. They don't eat on time, don't rest well, and these things cause pregnant mothers to become weak and have lack of strength. A complication that is always happening to mothers when giving birth is bleeding and no strength.

Similarly, a nurse in Vemasse remarked on the stark disparity between government statements regarding a healthy population and the realities faced by Timorese women.

In order to prevent child death, I want to quote what the government is always saying, 'povu forti nasaun forti' (people strong, nation strong), but I don't know what they mean by this. In order to accomplish this, mothers need to eat nutritious food and drink to have healthy babies. This is not the case here.

This view was echoed by a TBA who had worked for over thirty years in Venilale.

Timorese children's condition is not good, they don't have a good place to live, some do not have good food, some people do not have any food… When we watch TV we can see mothers that look young and healthy after giving birth, babies that are fat and healthy that look like they are 8-months-old even when they are actually only 3-months-old. Why do our women and babies continue to be so skinny?

Gender inequities are compounded by the other financial and non-financial barriers identified, and these in turn are exacerbated by the over-stretched and under-resourced health system. Case Study 4, above, illustrates the negative outcomes on maternal and child health in such a constrained environment.

Father and daughter, Baucau Hospital, Baucau District

Solutions to barriers identified and drivers to care seeking

Having highlighted the barriers and deterrents faced by caregivers in seeking treatment for childhood pneumonia and diarrhoea and in relation to skilled birth attendance and newborn care, participants were also asked to share ideas and possible solutions to overcome the challenges identified. They were encouraged to consider what, from their perspective, would lead to the adoption of healthy behaviour and appropriate and timely care seeking for childhood illness. Although practical measures to improve care-seeking behaviour were suggested, caregivers found it difficult to discuss solutions in the abstract, particularly in relation to financial and socio-cultural barriers. As one mother concluded, '*We don't like to get these kinds of sickness, but how are we are going to overcome our situation? I don't have an answer*'.

Other interlocutors, particularly TBAs, religious and community leaders and health staff were more adept at listing practical, often institutional solutions to increase the capacity of the health service delivery. Solutions to access barriers, health facility deterrents and knowledge and information barriers elicited the most animated and detailed responses. Several participants were, however, noticeably hesitant to suggest solutions to issues they felt were related to government control and therefore out of their remit. A doctor in Ermera remarked, '*For us we cannot directly recommend these solutions because you should pass through the bureaucracy of the system first*'.

All suggested solutions were analysed in relation to qualitative and quantitative data collected through the study. For ease of reference, the solutions raised by participants are presented according to the five thematic barriers identified in relation to care seeking and treatment. Table 6, at the end of the chapter, summarises the key barriers and solutions identified by community participants.

Solutions to financial barriers

No caregiver was able to envision a way to ease the financial burdens they incurred from transportation costs to and from clinics. Free ambulances or 'clinic cars' were not suggested as a viable alternative to public transport as caregivers perceived their child's condition to be 'routine' or 'common' and not severe enough to warrant emergency medical assistance. Financial barriers were not discussed in terms of out-of-pocket expenditure for medicines, and no solution to overcome these surprise or additional costs was discussed.

Solutions to access barriers

The most frequently forwarded solution to access barriers was to increase the number of ambulances and clinic cars for emergency situations. Although participants recognised that in some rural settings vehicles were not always able to navigate the difficult terrain, still greater coverage of emergency transport was seen to be beneficial. As a mother in Baucau stated, '*We want to request the government to provide a car for each village so when people are sick in case of emergency then they can use the car to come to the clinic*'. Such sentiments were repeated across all districts and participants concluded that the distribution of ambulances needed to be based on population size, not the one ambulance per sub-district method currently employed.

An alternative solution to tackle access barriers was presented by Health Alliance International in relation to their mHealth programme *Liga Inan* (or 'Mobile Moms'). This pilot programme aims to improve maternal and child health outcomes by providing difficult to access communities with regular health information updates and reminders via SMS. The programme sends messages twice a week to women throughout their pregnancy and for six weeks after delivery. *Liga Inan* is discussed further in the chapter 'Technology use for behaviour change'.

To increase overall accessibility, several participants stressed the need to improve infrastructure, both general and health-specific, and in terms of physical infrastructure and human capacity. A doctor at the hospital in Baucau concluded,

To the government and especially to the Ministry of Health that is now fighting to decrease morbidity and mortality rates for mothers and children, we want to tell them they need to improve human resources and road conditions and if they want to accomplish 2015 goals.

Solutions to health facility deterrents

Discussions about solutions to health facility deterrents emphasised the need for improved human resources for health, including increased capacity and capability, and better distribution of staff. In their focus group discussion in Baucau hospital, health staff explained,

Nurse 1*: Training for us is needed…*

Nurse 2: *To increase our capacity…*

Doctor*: More capacity building in relation to using modern equipment is needed and to send more Timorese to study in order to work on our own instead of depending on others for financing.*

Midwife: *Capacity building is needed to increase our knowledge on health because we only did our study during Indonesian times which was the same to secondary levels…*

Nurse 1*: Difficulties here are maintaining a work balance which means we need more nurses compared with the number of patients. The ideal standard is one nurse for four or five patients, but what we are facing now is one nurse for 10 or even more patients…*

Nurse 2*: Today we have 35 patients and only two nurses…*

Midwife: *Also, salary level for those who have been working since Indonesian times is very low.*

The need for increased training, specialisations, better health worker to patient ratio and improved salaries were reoccurring themes articulated by health staff and community leaders. As the sub-village chief in Venilale concluded, '*Services in terms of human resources is moving forward now but we need more doctors and nurses and midwifes. And one specialist doctor for children and mothers*'.

In Baucau, community leaders in Venilale stressed the need to improve current health facilities, stating that their local clinic had only one room for delivering mothers when at least four or five rooms were needed to accommodate the high demand. Similarly, a TBA in Vemasse emphasised that the local health centre was crowded and always busy, and suggested that a second health centre be built to increase positive health outcomes for mothers having difficult '*feet first*' deliveries. A mother in Railaco, Ermera, suggested that '*maternity home support'* should be given to mothers and basic supplies provided by the clinic '*for the poor ones who don't have anything at all*', specifically a sarong for mothers to carry their children properly, mats to sleep on, pails and buckets for drawing water, and basic medicines for '*diarrhoea, coughing, runny nose and itchy skin*'.

Health workers in all districts cited their need for increased medical supplies (particularly oxygen and resuscitation equipment) and essential medicines to treat pneumonia and diarrhoea. Health workers at Ermera Lama clinic also emphasised the need for more '*equipment to be used at the health centre*' and increased personnel, but as a senior member of staff added, '*getting these are based on the bureaucracy of the government system now, it depends on them*', suggesting that responsibility lies only at the central level. Interestingly, staff at Ermera Lama clinic also suggested that increased monitoring and evaluation was required to determine the efficacy of Ministry of Health programmes. Staff were keen to have a pilot programme on maternal and child health implemented in their area and for it to be monitored in terms of roll-out across other sub-districts.

Several TBAs recommended that partnerships should be fostered between traditional health providers who functioned at a community level and the local and district health facilities. A TBA in Venilale, Baucau, commented, '*Again, it depends on the government, if they recognise our value and if they call us then we could help in the hospital*. As highlighted above, the only facility visited where clinic staff had a close working relationship with their local TBAs was in Passabe. There, it was routine for both the traditional attendant and a clinic nurse to be present at home births in the area, and TBAs were encouraged to collaborate with the clinic. As one TBA commented, '*it is common we work together*'.

Solutions to knowledge and information barriers

As discussed, caregivers did not perceive their lack of knowledge or information on child health to be a barrier. Only in relation to the doctor's instructions to keep children away from 'dust and dirty things' in order to prevent sickness, did mothers in Pante Makasar, Oecusse, forward a concrete solution. In acknowledging that they could not readily change their immediate living environment, mothers suggested building a 'safe and clean' playground in the village where their children could play. As one mother concluded,

Children here are playing in whatever places they can find. There is no proper place for them to play, so if possible UNICEF could build a place for children to play which is clean and comfortable to prevent them for playing in the river or dirty places.

Because access to the SISCa programme and other NGO interventions (such as *Liga Inan*) was easier and more immediate than visiting a health facility, caregivers appeared to appreciate the information provided through these initiatives and implemented many of the recommended practices. Mothers recalled key messages gleaned from the SISCa programme to include: 'how to feed the baby'; 'to breastfeed only until six months'; 'how to use a mosquito net'; and 'how to clean the home and surroundings'. In discussing health education provided by NGOs, women recalled health promotion activities by Alola (on 'how to breastfeed'; 'how to carry the baby'; 'to give birth at clinic'), World Vision (on the 'importance of cleaning the environment'; 'how to breastfeed the baby'; 'how to make porridge with vegetables') and the World Food Programme (on 'additional food for babies experiencing malnutrition').

Other channels of information that caregivers mentioned were the promotion of baby booklets that women received when pregnant ('*I read and followed what was written there, for example eating fruits and drinking a lot of water*') and increasing the number of informative posters in clinic waiting areas and public places. A mother in Ermera Lama reported that she had not received any information on exclusive breastfeeding from health staff, but had read about it on a poster whilst visiting her local clinic for antenatal care.

Other respondents' suggestions for overcoming caregivers' limited knowledge most often involved using existing communication channels between community health staff, local religious leaders and key government services. In Baucau, a nun described the relationship between her Canocian community clinic and the Ministry of Health, '*There are some nurse-sisters in our congregation who provide information and do training. Also we have good links with the Ministry of Health to provide health services*'. A priest in Venilale emphasised the importance of regular dialogue between the local clinic and the church, as he attempted to provide his parishioners with health updates, '*Sometimes there is something from the clinic that they gave me to announce about disease… Among us we collaborate with each other*'. Similarly, religious leaders in Vemasse described giving out important health messages during Sunday church services.

Even though this is the health department's work, we always announce when there is a request or letter. For example there was an announcement when an eye specialist from Australia came. We said that for those who have problems with eyes you can go and see doctors from Australia that will do eye treatment on a big

ship. And also we made an announcement for those people who have problems with legs or arms to go and see specialist doctors. These are the kinds of announcements we make based on government requests or information from the health centre.

In Vemasse, the priest confirmed that church services on a Sunday had 80-90 people in the congregation, but that on important Catholic celebration days, attendance numbers could reach several hundred. A community health worker in Railaco, Ermera, explained that the majority of her health promotion activities were centred on important religious dates.

For two months, for May and October because this is the Month of the Rosary, Our Lady of Fatima's Month. For the whole month, every day we go house to house for those two months. For the rest of the year it is only once a month. We provide different kinds of information during the Month of Rosary, for example, if the clinic says there will be vaccines here on this day, then we will go and give this information on this day and this month. It depends on the clinic's plan. Based on this plan we will tell the people and the priests will make an announcement. For these two months, every day we do these activities.

Caregivers frequently recalled hearing health-related information during church services. A mother in Pante Makasar, Oecusse, confirmed, '*Just yesterday, at rosary last night, they announced that every child should go to the clinic for corn powder*'.

Solutions to socio-cultural and gender barriers

To counter the practice of *tur ahi* ('sitting fire') both TBAs and NGO staff proposed practical solutions that would satisfy the need for mothers and newborns to remain warm, but without the risk of smoke inhalation caused by the open fires. Alternatives suggested included mothers having hot drinks, bathing in hot water, and wrapping the baby in warm clothing. Promotion of such activities, paired with health messages that stressed *tur ahi* could be harmful, was the most cited method to reduce maternal and child pneumonia.

To promote health behaviour and family planning, Health Alliance International had produced a range of films to be screened to community health workers and community members in villages and sub-villages across six districts in Timor-Leste. One film addressed how women could mediate with family members who were in a position to influence their location of delivery. A representative from Health Alliance International explained,

In Timor everyone has a say in where you will deliver. Your family has a say, your neighbours have a say, your grandparents… and because of this we remind women that they need to discuss their plans with their families early so that they will have time to plan for where to deliver their babies, to have a consensus as to where to give birth.

Another film featured respected religious figures discussing the benefits of family planning. The representative confirmed,

We have a family planning movie that involves a bishop in the movie to show that family planning is ok. Family planning messages must be coordinated with the church. Some priests are ok to discuss this with and some are very difficult to discuss these things with. Most priests that promote family planning promote the natural method of birth spacing, called the 'Billings method'. This is the family planning method promoted most frequently in Timor. Though in our movie we do not say what method to use. We say instead, and have the bishop confirm this message, that women should discuss all of their options with health professionals and then decide on what method of family planning is right for them.

After a screening, further dialogue on health issues would be facilitated. According to Health Alliance International, it was evident based on these discussions, that the majority of women preferred to receive injections rather than use the Billings method of birth control.

Table 6 – Summary of barriers identified and suggested solutions

	Identified barrier	Suggested solution
Financial barrier	• Transportation cost	[No solution suggested]
Access barrier	• Lack of transport (both public and ambulance) • Distance from health centre • Poor road conditions (especially in raining season)	• Provide more ambulances • Introduce mHealth • Improve road conditions (although this is beyond the ability of the health sector alone and requires substantial investment in the country's infrastructure, particularly in rural areas)
Health facility deterrents	• Limited clinic working hours • Lack of staff • Poor attitude of health professionals • Lack of medical equipment and facilities • Frequent stock-outs	• Ensure adequate space and privacy for labouring mothers • Build additional facilities, designate specific areas as delivery units • Provide mothers with basic commodities (sarong or hospital robe etc.) • Improve health professionals' communication skills • Develop partnerships between TBAs and health facilities • Improve human resources for health (number of trained staff and their distribution) • Refresher in-service training and continued professional development • More effective supply chain management • Establish maternity waiting units
Knowledge and information	• Low demand for health education by mothers • Limited sources of health information • Unprofessional PSFs	• Leverage existing local networks to provide health information, particularly through the SISCa programme • Develop SBCC materials and resources for use in health facilities and other community areas • Train health professionals in communication and counselling skills • Utilise influential community members and collaboration between health facilities and the church • Provide additional training to PSFs
Socio-cultural barriers including gender	• Persistence of customary practices • Lack of family planning • Limited empowerment of women and reduced agency to act • Inability to control dirt and dust in home environment	• Increase levels of health education and target wider community with key messages • Promote culturally acceptable practices as alternatives to risky or potentially harmful practices • Make use of religious endorsements and influential community members to encourage family planning • Develop a safe and clean playground for children

Mother and son, Ermera Lama, Ermera District

Technology use for behaviour change communication

mHealth overview

In recent years, innovative technological solutions have been proposed, piloted and monitored for extending the coverage of skilled healthcare to include even the most remote areas. One of the most promising initiatives is mobile health, or mHealth: health related practices that are supported by mobile devices providing a direct link to the target beneficiaries for the use of data collection, real-time patient monitoring and healthcare communication. The World Health Organization defines mHealth as 'medical and public health practice supported by mobile devices, such as mobile phones, patient monitoring devices, personal digital assistants (PDAs), and other wireless devices' (WHO 2011). With approximately 5 billion mobile phone users globally, 73% of whom live in developing countries, the role of mobile technologies in both preventative and curative health services, particularly in low- and middle-income countries (LMICs) is steadily increasing (Marshall et al. 2013). Nearly 90% of the world is now covered by a wireless signal, ensuring that formerly isolated individuals, such as mothers in rural villages in Timor-Leste, have the potential to access these technologies (Lemaire 2011). mHealth can also support healthcare workers, particularly in rural locations with limited infrastructure where community health communications may be the vital link for patients to access correct and timely treatment (Mishra and Singh 2008).

mHealth has the potential to address many of the challenges faced by weak and under-resourced health systems including shortages of skilled workers, lack of timely reporting for surveillance and diagnostics, poor treatment adherence and poor inventory and supply chain management (Marshall et al. 2013). Uptake has been especially high in emerging markets, where limited landline infrastructure has led to greater reliance on mobile networks for everyday communication (Mechael 2009). In fact, the ability to serve areas lacking in landline infrastructure can be helpful in terms of disease surveillance as mobile Global Positioning System (GPS) technologies can assist in the triangulation and tracking of outbreaks and epidemics (Marshall et al. 2013).

Free et al. (2013) note that the amount of information and support that can be conveyed to individuals through traditional media, such as leaflets, or even basic medical consultations with professionals, is often limited, but that mHealth has the ability to deliver health messages to people anywhere and at the most relevant times. mHealth breaks down financial barriers as well as those caused by lack of education and socio-cultural determinants, and is able to reach families and communities as a whole. As Källander et al. (2013) conclude, 'By harnessing the increasing presence of mobile phones among diverse populations, there is promising evidence to suggest that mHealth can be used to deliver increased and enhanced healthcare services to individuals and communities, while helping to strengthen health systems'.

Leroux and Rivers (2013) look to mobile phones as behaviour change communication devices, highlighting the need for simple but effective messages relating to hygiene (washing hands with soap, cooking food properly, washing fruit and vegetables) to assist in combating a high prevalence of diarrhoea thereby achieving the biggest impact at the lowest cost. Text messaging interventions have been shown to increase adherence to antiretroviral therapy in low-income countries and smoking cessation in high-income countries (Free et al. 2013). Short Message Service (SMS) has been forwarded as the most simple and cost-effective mHealth measure, although challenges have been noted in fitting health messages within the 160-character limit of text messages, particularly when a project's catchment area contains more than one spoken language. Mechael et al. (2010) highlight the need for more sophisticated, patient-specific messaging systems to be developed.

It is estimated that 30–70% of all health information technology projects fail (Kaplan and Harris-Salamone 2009), and it is reasonable to expect that mHealth projects would parallel this rate (Marshall et al. 2013). Several authors have commented on the fact that the majority of mHealth evaluations have focused on interventions in the global North, thus providing little evidence for efficacy in LMICs (Gurman et al. 2012;

Free et al. 2013; Mechael et al. 2010). In addition, a large portion of the research is concentrated solely on initiatives corresponding to HIV/AIDS, tuberculosis and malaria, and it remains unclear whether the effectiveness of these interventions is influenced by setting or participant demographics. While the integration of mHealth into prenatal and newborn health services has demonstrated positive early outcomes in some contexts, evaluations that address impact and sustainability require further feedback from on-going programmes (Tamrat and Kacknowski 2012). Studies are yet to prove that social behaviour change communication (SBBC) through mHealth results in significant effects on the intended audience (Free et al. 2013). The initial signs are encouraging, however, and mHealth has an important role to play in accelerating progress towards the MDGs.

Mapping the mobile landscape

In light of the potential benefits of mHealth technology for reaching rural or marginalised populations in Timor-Leste, the research team collected data related to specific mobile phone use and preferences as well as additional data related to television, radio and Internet use (see Appendix 3 for the questionnaire). This chapter collates qualitative data from in-depth interviews and focus group discussions, and quantitative data gathered through the technology surveys.

Overview of current mobile phone usage and constraints

Of the primary caregivers interviewed in Baucau (n=10), four did not have a personal mobile phone. All but one of these, however, had access to a phone via their husband or close relative. Of the six women who did have a personal mobile phone, only one mother of a newborn had ever used it for a health related call – to call the ambulance when she went into labour. She reported that she knew the appropriate number to call because the ambulance driver was a relative. Other caregivers interviewed in Baucau stated that they did not know what number to call for their local healthcare workers or ambulance service. With regards to calling an ambulance in an emergency situation, most felt they did not have the authority necessary to make such a call themselves, but would defer to appropriate health workers or community leaders. A mother whose child was hospitalised with diarrhoea in Baucau, explained '*I went to the nurse and the nurse contacted the ambulance*'. A PSF in Caicua Village, Vemasse confirmed, '*I am the coordinator of this area, so if there is somebody sick, then I will call the ambulance for them*', whilst a sub-village chief in Venilale explained, '*Each village chief and sub-village chief has a phone and if there is somebody sick then they can contact the chief to call the ambulance… That is my job in accordance with law number three of Timor*'.

None of the TBAs interviewed in Baucau had a mobile phone. If their services were required, clients or the relatives of clients would go to their home and request their services in person.

Of the primary caregivers interviewed in Ermera (n=9), four did not have a personal mobile phone, although all had access to a phone through their husband or relatives. As in Baucau, it was unlikely that caregivers had ever called health workers or the ambulance service directly. A mother of child with pneumonia at Gleno hospital concluded, 'No*, we cannot call because we don't have the number of the doctor or the ambulance*'. Only one caregiver in Ermera, a father whose daughter had been hospitalised with pneumonia on multiple occasions, had the number of the ambulance to call in an emergency situation. A mother of a newborn in Gleno reported that she had used an ambulance once during her pregnancy after she had an episode of dizziness and had fallen, but only because her brother was a nurse at the hospital and knew the ambulance driver. She explained, '*I have never contacted the ambulance, but my brother is a nurse so when one of us gets sick we call him and he is the one who calls the ambulance to come. We don't call the ambulance directly*'.

Both of the TBAs interviewed in Ermera had a personal mobile phone, although this was not the method by which mothers would contact them. A community health volunteer in Railaco explained that in her rural area, families who required emergency assistance needed to contact a nurse at one of the two health

posts, either by going in person or telephoning their personal mobile number. The nurse would then call the clinic on their behalf. She emphasised the patients '*don't call directly, they have to pass by one of these two health posts*'.

Of the primary caregivers interviewed in Oecusse (n=9), five did not have a personal mobile phone and two (one in Passabe, one in Pante Makasar) did not have any access to a phone. In Passabe and Oesilo caregivers described that it was difficult to keep their phones charged due to the limited supply of electricity. A mother in Oesilo explained that her husband had a small solar battery they used for charging the phone, whilst another confirmed that she and her husband had to travel to Oecusse (a 90 minute drive) in order to charge their two phones. At the time of the interview, neither of these caregivers' phones were functioning.

None who participated in the fathers' focus group discussion in Pante Makasar (n=5) had a personal mobile phone. In contrast, participants in the mothers' focus group in Pante Makasar (n=6) suggested that owning a phone was increasingly common for Oecusse residents. Four of six participants had a personal mobile phone.

Now is different if we compare with before, now almost everybody has a phone even though they don't have much money. So at least there is one mobile phone in a house. And if they don't have one, then it is easy to borrow from neighbours.

For all caregivers, regardless of whether they had a personal mobile phone, health assistance would be sought directly at the clinic or from a health worker. No participant reported using their phone in relation to seeking health advice or treatment. None of the TBAs in their focus group in Passabe (n=6) had a mobile phone. They concluded, '*People send somebody to pick us up. We have no telephones*'. Table 7 presents the demographic details of technology survey respondents in each district (n=90).

Table 7 – Demographic details of technology survey respondents in each district

	Baucau (n=35)		Ermera (n=27)		Oecusse (n=28)	
Relation to child	Mother	31	Mother	26	Mother	24
	Father	2	Adopted mother	1	Father	1
	Grandmother	2			Uncle	2
					Brother	1
Age range	Mothers	19-42	Mothers	21-35	Mothers	18-38
	Father	31-40	Adopted mother	34	Father	45
	Grandmother	45-57			Uncles	21-29
					Brother	21
Marriage	Married	34	Married	27	Married	25
	Divorced	1			Single	3
Children in care	No. of children	1-3	No. of children	1-3	No. of children	1-3
Religion	Catholic	35	Catholic	27	Catholic	28
Education level	None	10	None	1	None	4
	At least primary	25	At least primary	26	At least primary	24
Income range	Monthly USD	0-380	Monthly USD	0-500	Monthly USD	0-460
Mobile phone users	% of respondents	62.9	% of respondents	59.3	% of respondents	85.7
Television users	% of respondents	71.4	% of respondents	74.1	% of respondents	82.1
Radio users	% of respondents	62.9	% of respondents	66.7	% of respondents	39.3
Internet users	% of respondents	2.9	% of respondents	7.4	% of respondents	3.6

68.9% of caregiver survey respondents (n=62) had a personal mobile phone. The most common cell service provider was Timor Telecom, the network used by 66.1% of all respondents with a mobile phone. Following Indonesia's violent withdrawal from Timor-Leste in 1999, the national telecommunications infrastructure

was largely destroyed. In the absence of formally well-established Indonesian mobile phone companies, Timor Telecom began operations in 2003. Respondents also reported using Telemor and, just in Oecusse, Telcomcel (see Table 8).

Table 8 – Mobile phone service providers

Service provider	% of technology survey respondents
Timor Telecom	66.1
Timor Telecom & Telemor	19.4
Telemor	8.1
Timor Telecom, Telemor & Telcomcel	3.2
Telcomcel	1.6
Timor Telecom & Telcomcel	1.6

In Baucau and Ermera, phone reception was described to be generally good. In Oecusse, however, two respondents in Passabe had to climb to an elevated location to make or receive calls, and in Naimeco *suco* (Pante Makasar sub-district), seven respondents had to travel to either Nunete or Fatuknao *aldeias* to find better reception.

The majority of respondents described their phones as being charged and ready to use every day. Those who did not charge their phones everyday were more likely to have no credit at the time of the survey. Of those who participated in the survey, 56.5% (n=35) had mobile phones currently with credit. One USD was the most commonly purchased credit denomination for topping up pay-as-you-go phones.

With regards to text messaging, only two respondents, both in Oecusse, stated that they did not send or receive text messages. Six other respondents across all three districts reported that they did not send text messages, but did receive text advertisements from their mobile provider. Mass text messages are frequently sent to Timor Telecom customers with promotional offers. A media survey conducted in 2011 by UN Integrated Mission in Timor-Leste (UNMIT) found that 68% of Timor Telecom customers could remember the last promotional text message sent by the company (UNMIT 2011). Only one participant in Baucau (Caibada Makasae) said they received text messages from their sub-village chief and village council on matters affecting the community.

A summary of key data related to mobile phone practices (both calling and texting) is presented in Appendix 7. The tables include demographic details of each caregiver who participated in the technology survey (location; age; relationship to child; monthly income range) and whether or not their phones had credit at the time of the survey. The table also presents who the caregiver most frequently called and sent text messages to, who they received calls and text messages from and details of their service provider. Additional technology data (provided in subsequent tables) details how often television, radio and Internet were used, favourite programmes, approximate time and day of usage, and duration spent using different technologies.

Other technologies

Television and film

Television usage was common throughout all districts with the exception of Passabe sub-district in Oecusse due to poor electricity supply. 75.6% of participants (n=68) watched television on a weekly basis. Favourite programmes were reported to be the news (by 64.7% of respondents), movies and music shows. Radio-Televisão Timor-Leste (TVTL), a local Timor news channel, was the most frequently watched channel with the Indonesian language channels Indosiar and Indonesian TV being the second most watched channels. Time spent watching television ranged between ten minutes to six hours per day, with between 30 minutes

and two hours being most common. The majority of television watchers reported the evening, specifically 8 pm, to be the time of day when they would turn on their television. (See Tables in Appendix 7).

Radio

Radio is widely perceived to be the most popular media for communication in Timor-Leste. The UNMIT media study concluded that radio has the greatest reach of all communication channels with television a close second (UNMIT 2011). The Demographic Health Survey (2009-2010), however, indicated that just over a third of women were regularly exposed to radio, suggesting that their access to radio was diminished in comparison to other community members. In Baucau, 57.4% of women had regular exposure to media less than once a week; 63.7% in Oecusse; and 67.5% in Ermera (NSD/MoF/ICF 2010).

56.7% of the technology survey respondents (n=51) had radios themselves or were able to listen to radios owned by family or friends. Radio Maubere and Radio Nacional de Timor-Leste (RTL) were most often reported to be respondents' favourite stations and news and music programmes listed as most popular. Interesting, a mother in Ermera indicated that her favourite programmes were those providing '*information about women's rights*'. She was the only respondent who listed 'Radio Voz' as her favourite station. Radio Falintil/Voz da Esperanca (or Radio Voz) is a community station that was operated clandestinely by Timor-Leste rebels before Independence. Despite all survey participants reporting to be Catholic, no one suggested Radio Timor Kmanek (RTK), Catholic church radio, as their favourite station.

There was no standard timeframe in which respondents listened to the radio, with diverse listening hours including early in the morning (7am) and late in the evening (9pm). The time spent listening to the radio was less than that spent watching television, with most respondents suggesting they listened for an hour or less per day. In Passabe, Oecusse, where electricity shortages were common, only one respondent listened to the radio. (See Tables in Appendix 7).

Internet

Only 7% of Timorese access the internet (UNMIT 2011). Although internet cafes are widely available in the capital city of Dili, they are virtually non-existent elsewhere in the country. Timorese who live outside the capital and who wish to access the internet usually possess their own modems. Only four survey respondents (4.4%) had access to the internet: one in Baucau, two in Ermera, and one in Oecusse. The income levels of these individuals averaged USD 250 per month, far higher than the salaries of most participants. They reported to use the internet for checking Facebook, accessing email, conducting job searches, looking for information, and in the case of one 20 year-old mother, for her school assignments. (See Tables in Appendix 7).

Health-orientated programming

According to Freedom House, a US-based NGO conducting research on journalistic freedom and human rights, Timorese journalists frequently self-censor themselves and/or quote official documents verbatim for fear of prosecution (Freedom House 2013). Anecdotal evidence from Ermera suggests that radio DJs still continue a practice which began 'during Indonesian times' of using on-air pseudonyms to protect themselves from potential prosecution. Although such censorship is unlikely to influence much health-orientated programming, it should be considered in relation to more sensitive issues such as family planning.

After Independence in 2002, broadcasting has been dominated by public radio and television outlets, although community radio stations have started to play an increasingly important role in the media landscape. Many local stations are backed by international funding (UNMIT 2011). UNICEF, for example,

supports a local radio station in Gleno, Ermera. Broadcasting on 92.3FM, maternal and child health programmes are aired every Tuesday.

Several NGOs broadcast health-related films at the community level, and sponsor short television spots, although they do not run mass media campaigns on television. CARE, for example, implements 'Night Event', and Health Alliance International and Childfund have similar programmes. These initiatives screen social-marketing films on various health topics, such as encouraging mothers to attend the SISCa programme. As discussed above, the film sessions are followed by discussions with audience members to share their experiences and provide a forum for engaged health education.

In terms of mHealth, Health Alliance International started to pilot their programme *Liga Inan* (or 'Mobile Moms') in early 2013. As mentioned above, this programme aims to improve maternal and child health outcomes by providing difficult-to-access communities with regular health information updates and reminders via text message. The programme sends SMS messages twice a week to women throughout their pregnancy and for six weeks after delivery. The text messages are coordinated and approved by the Maternal and Child Health Department at the Ministry of Health and include: upcoming dates for antenatal care; information about when and where the SISCa programme will operate; reminders about birth planning and preparation to encourage women to deliver at a health facility; reminders to have proper nutrition. Since early spring, the pilot project has been running in four sub-districts of Manufahi district, where 66% of mothers have their own phone or access to a family phone. According to Health Alliance International staff, initial results are promising, with a notable increase in the number of facility-based deliveries since the start of the programme.

Mother and son, Pante Makasar, Oecusse District

Conclusion and recommendations

The formative research undertaken with caregivers, traditional birth attendants, community and religious leaders, and health professionals in Baucau, Ermera, and Oecusse districts, has documented new empirical data on preventable child deaths from pneumonia, diarrhoea and newborn complications in Timor-Leste. The research identified barriers that prevented communities from adopting healthy behaviours and best practices for timely and appropriate care seeking, and the positive motivations and triggers that contribute to an enabling environment and support communities to seek care.

The evidence generated through this research should now be operationalised and used to inform future programme design and communication strategies as UNICEF supports Timor-Leste in their pledge, 'A Promise Renewed', to focus on under-served populations and end preventable child deaths. In working towards this goal, integrated child survival strategies (incorporating health, WASH and nutrition) are imperative. To conclude, five interrelated areas of intervention are highlighted and associated recommendations made.

1) Core areas for communication interventions

Key communication for development objectives for Timor-Leste intend that mothers of under-fives, as well as mothers-in-law and husbands, will know the danger signs of pneumonia and diarrhoea and be able to seek timely care and support from appropriate healthcare providers. Respiratory infections and diarrhoea currently account for the highest burden of disease and death amongst Timorese children (Deen et al. 2013; Bucens et al. 2013). The majority of mothers in both Baucau and Ermera (more so than in Oecusse) were able to identify symptoms of pneumonia, and caregivers in all districts suggested clean environmental conditions as the primary method of preventing disease. Mothers frequently cited health workers as the source of their knowledge to keep children from playing 'with the dirt and dusty things', however, they were just as likely to reiterate their inability to accomplish this goal given their current socio-economic status (residing in a house with a dirt floor) and local environment (living next to dusty unpaved roads). Because of these constraints, there was a perception that pneumonia could not be prevented. In addition, mothers in Oecusse were more likely to report that pneumonia was caused by external physical trauma to a child's chest rather than a condition originating in the lungs.

The majority of mothers were able to identify symptoms of diarrhoea, however attributed causes were highly variable across the three districts with a combination of physical and spiritual reasons cited. Understanding of prevention and the associated measures that were adopted were equally diverse in scope. The 2011 KAP study on water, hygiene and sanitation concluded that Timorese caregivers often failed to link hand washing with disease prevalence, particularly with regards to coming into contact with children's faeces (Mattson 2011). This finding is reinforced through the current research that indicated caregivers' knowledge on hygiene and sanitation was low and there was a marked discrepancy between practices reported and observed.

Regarding care-seeking for childbirth and the location of delivery, Timor-Leste is in a period of transition. Younger women and those with fewer children expressed a preference for facility-based delivery as it enabled better access to medical equipment and skilled health workers. Older women with more children and those living in remote or rural areas tended more towards home delivery, in privacy attended by their family or local TBA. Past experiences of uncomplicated births and the historical precedent for home deliveries were contributing factors (Wild 2009; Zwi et al. 2009). In contrast to caregivers' knowledge on childhood illness, their knowledge about pregnancy was relatively high, particularly with regards to exclusive breastfeeding, although mothers tended to supplement or withdraw breast milk if they perceived it to cause diarrhoea. This finding corroborates results from the World Bank review of the health sector (World Bank 2006).

Based on the research, the following are key areas that communication interventions should target:

- Improving caregivers' knowledge of illness symptoms, the progression of illnesses and timely care seeking should be a priority in all three districts to counter the perception that some symptoms can be disregarded as routine. It is particularly important to highlight, for example, that drowsiness and lack of appetite are danger signs of childhood illness as many mothers only acknowledged crying as being problematic. Similarly, caregiver misconceptions regarding the causes of illness must be addressed.
- Communication interventions should focus on issues of disease prevention. The concept of prevention is poorly understood and this should be directly addressed in relation to both pneumonia and diarrhoea. This has implications for the key health messages health professionals communicate to caregivers and demonstrates a need to further invest in interpersonal communication (IPC) and IMCI approaches.
- Key WASH messages should also focus on prevention, linking hand washing and sanitation procedures to disease prevention. Measures should be easy to incorporate into daily routines, such as boiling water prior to consumption (particularly in Oecusse) and removing children's faeces promptly. Reported practices of using washing detergent for bodily hygiene at home (when soap was not available) should also be reinforced. In addition, the misconception that the risk of food and water contamination is elevated during the raining season, needs to be addressed.
- Caregivers who did not present their child for 'routine' or 'common' illnesses were also dissuaded from attending health facilities due to travel times, associated costs and frequent stock-outs. In some sub-districts health workers promoted the use of homemade rehydration solutions as a viable alternative to ORS. Caregivers should be encouraged to give ORS or equivalent at the onset of diarrhoea and other illness episodes, and the correct measurements of salt/sugar/water should be stressed. This should be acceptable to, and easily actionable for, caregivers as it would complement the widespread custom of using plant-based medicines prepared at the household level.
- In continuing to promote exclusive breastfeeding and maternal and child nutrition, key messages should purposively address the concerns mothers articulated about breast milk causing diarrhoea.
- Newborn danger signs should be emphasised, particularly the need for special care for low-birth weight and pre-term babies. Postnatal care should be strengthened and relevant messages included in the support materials for SISCa workers.
- The negative effects of post-natal seclusion and *tur ahi* should be made explicit and the practice slowly and gently modified to reduce the level of potential harm. In this regard, C4D could adopt a phased or incremental approach to behaviour change. For example, the strategy may first focus on the provision of ventilation in the room prior to the mother and baby emerging for vaccination.
- Negative attitudes expressed by healthcare workers has been reported by caregivers as contributing to their delay in and/or lack of treatment seeking at health facilities. C4D activities should aim to improve the attitudes of health professionals to ensure equitable treatment.
- It is important to engage all potential health providers (including *matan dook*) and target them through specific C4D strategies. For example, it should be better communicated to TBAs and *a samat* that using massage to correct birth positioning may be particularly dangerous if done forcefully, and can lead to placental separation and antepartum haemorrhage.

Connecting each of the above areas is the overarching need to further empower women so they have the agency to act. Several of the community-generated solutions discussed above addressed issues of dependency. Communication interventions therefore need to target the community as a whole, with activities on maternal and child health implemented for youth, men, older women and community and religious leaders as well as for women of reproductive age. Key messages should emphasise that a woman's health increases the productivity of the whole family unit.

Future interventions need to incorporate this overarching goal so as not to reinforce negative barriers that prevent care-seeking behaviour. For example, the scarcity of ambulance resources in all districts was found to reinforce women's perception of themselves as low-status individuals who lacked authority to request emergency services. Instead, such requests were routed through persons perceived to be in authority, more respected or of a higher community standing. The system of accessing emergency care was found to replicate the power dynamics at a household level, where the majority of women had to defer to their husbands and in-laws for healthcare decisions.

2) Opportunities for the adoption and promotion of appropriate healthy practices and actions

A key opportunity for the promotion of healthy practices and actions that was not being maximised was attendance at health facilities. It was striking that the majority of caregivers reported that no health education or information was provided at health facilities, whether they attended routinely or only during episodes of child illness. The success of the SISCa programme in relation to improving knowledge about pregnancy and childbirth and increasing the number of ANC visits and child immunisations demonstrates that appropriate health information, when it is locally available is both valued and often acted upon. Similarly, the timing of health education at the community level is important, both in terms of caregivers' expectations and receptiveness, and the ability to achieve widespread distribution of key messages. Identifying and maximising opportunities for the promotion and adoption of healthy behaviours, requires the development of community agency and the promotion of local solutions, particularly in rural contexts where investment in the health sector is limited.

The following are key opportunities to enable caregivers, communities and healthcare personnel to adopt and/or promote appropriate healthy practices and actions:

- Improving the quality and quantity of health education provided at health facilities is a central priority. Direct and indirect communication is required. Appropriate Social Behaviour Change Communication (SBCC) materials should be developed and introduced across the target areas. Importantly, health professionals should receive training on communication and counselling skills, and should be provided with necessary Information Education and Communication (IEC) aids to deliver effective health education.
- The potential of introducing maternal waiting homes should be considered. Although challenging due to lack of funding and already stretched human resources, maternity waiting homes may yield dividends in terms of providing increased access and serve as a valuable opportunity to promote health education. In addition, the provision of hospital robes for all labouring mothers should be considered. This may encourage mothers who previously were reticent to attend due to lack of appropriate clothing.
- The SISCa programme has achieved a high level of coverage and penetration and should be supported to provide targeted health education on pneumonia and diarrhoea and childhood illness.
- The church is a formidable channel for promoting health activities. Health facilities should maximise their collaboration in the Month of the Rosary and around other Catholic celebrations to mobilise community volunteers who go door-to-door in the months of May and October to convey relevant and timely health messages to the communities they serve.
- The opportunity to collaborate with local health providers including TBAs, *a samats* and healers (particularly *matan dook*) has not been well developed. Such health providers are trusted and respected members of the community whose influence and social agency should be better harnessed. With appropriate support they could distribute and reinforce key health messages and promote specific behaviours and practices. In Oecusse, TBAs worked collaboratively with health clinics. Both TBAs and nurse/midwives assisted in home deliveries, particularly in rural areas or where there were no separate facilities for labouring women at the local clinic. Further study is required to see if this leads to improved health outcomes, but it was perceived to be beneficial by the community, TBAs and health

workers alike. As a way to improve the coverage of skilled assistance at birth, it could be piloted in other sub-districts.

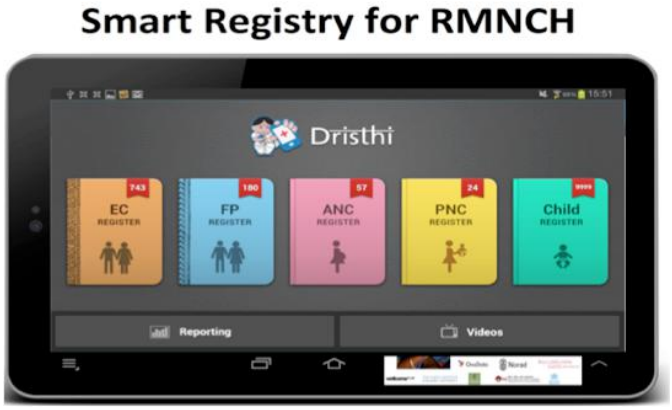
- Similarly, local community support groups have reach and influence across communities and should be harnessed to promote appropriate health practices and actions.
- The viability of introducing conditional cash or commodities transfers for TBAs (for example if they referred mothers and engaged with programmes) has been shown to be an effective and efficient incentive in similar contexts, and could be considered in Timor-Leste.
- The literature reviewed suggested that information conveyed by school children to household members was generally held in high regard (Earnest 2004). School based health promotion activities should be further explored and utilised as a method to disseminate key health information to the community.
- Developing safe and clean community playgrounds may create environments that prevent children from playing in dusty streets, and be a valuable resource for mothers with several young children who are difficult to supervise adequately. The C4D positive deviance approach can be used to illustrate how caregivers may contribute to safer child play areas by sprinkling their courtyards with water to avoid dust.
- Optimal birth spacing and its link to improved maternal and child health should be routinely promoted, but should specifically target families experiencing unemployment, particularly those with out of work male household heads.

3) The feasibility for introducing mHealth

The social media landscape of Baucau, Ermera and Oecusse Districts were mapped in detail. The highest percentage of caregivers with personal mobile phones used for calls and text messages was in Oecusse (85.7%), yet several sub-districts in this Timorese enclave were subject to electricity problems and poor network coverage. Baucau and Ermera districts had a significantly lower percentage of primary caregivers with personal mobile phones (62.9% and 59.3% respectively), yet reported no electricity or coverage issues. In addition, the low average monthly incomes of research participants indicated that buying regular credit for phones may be problematic. The most frequently purchased denomination of phone credit was USD 1. This was also the average cost of a one-way trip to the local health centre using public transport and many caregivers perceived this expenditure to be a financial barrier negatively affecting their care-seeking behaviour.

It is difficult to assess how receptive individuals would be to adopting a new and potentially disruptive technology and, in the abstract, it was challenging to determine the level of demand from caregivers or health professionals. With this caveat in mind, three points should be highlighted. First, given that caregivers did not call ambulance services and rarely called health workers, it may take substantial education to convince users that mobile health phones can be an effective health communication tool. In addition, because people were used to passively receiving promotional text messages, it may take time for caregivers to distinguish between commercially focused marketing texts and messages that require them to enter into dialogue or take health-orientated action. Whilst this should not deter programme implementation, it should be taken into consideration during the planning and design phase of pilots, whereby one-on-one recruitment and training of caregivers would be optimal. Secondly, community and religious leaders and health workers viewed themselves as important relay points in communication between a patient and a health facility. It is important that they be included in programme design and roll-out, to encourage community ownership and reduce tensions resulting from non-compliance with customary communication paths. Thirdly, advances in SMS should not negate the need for increased interpersonal communication between health professionals and patients. Increasing the responsiveness of doctors to patient needs during hospital/clinic consultations will only increase the value of SMS-based messages when face-to-face consultations are not possible due to distance.

In relation to the use of mHealth and other technologies by health personnel, it may be useful to consider the use of low-cost tablet computers for SISCa staff. There have been several promising health technology initiatives that have engaged community health workers by providing them with low-cost mobile devices to show instructional videos and other visual media to primary caregivers.



Some of the most promising mHealth applications that support community health workers not only deliver timely health education information, but also provide the capability to collate, track and monitor all routine Maternal Newborn and Child Health (MNCH) heath data, typically collected by a mobile workforce. Dristhi, the Smart Registry application system, has the potential to assist SISCa staff and other community health workers with compiling current registers, collecting data and the timely reporting of health events. This technology, currently being developed by WHO (among others), offers a promising mHealth platform for maternal and child health. Dristhi eliminates paper-based records and works offline to link health information (that is both relevant and timely) and provide better reporting and monitoring of clients. Each of these factors represents particularly useful advancements for community-based interventions.

CommCareHQ is another positive mHealth option that could potentially increase the capacity of health workers in their outreach activities. This technology utilises SMS for data collection with Java-enabled mobile phones (ideal for areas with limited wireless or 3G access), and automated text or voice message alerts reminding caregivers of appointments or providing timely health information triggered by upcoming events (such as pregnancy due dates). CommCareHW serves as a job aid for a mobile workforce and captures large amounts of data for storage in an electronic repository, which again eliminates the need for cumbersome paper-based records.

In terms of the feasibility of introducing mHealth, a side of the equation not explored during this research was the technical capacity of the health system to support appropriate mHealth interventions. This would necessitate close collaboration with the telecom providers, at least initially, and for any intervention to be successful, appropriate resources and time must be allocated for design, implementation and ongoing monitoring and evaluation.

The findings of this research suggest that currently, the capacity of the telecom network to support mHealth interventions is limited, particularly in relation to poor network coverage, the expense of phone credit and sporadic sources of electricity. However, the World Bank and other development partners are supporting telecommunications reform in Timor-Leste in collaboration with the government and private sector. These efforts have resulted in licences being issued for multiple telecom operators, the introduction of regulations that promote much-needed competition in the market and the development of a programme to support universal mobile and internet access in commercially less viable areas of the country. In light of this, it would be critical to agree with service providers on a basic or standard option package to support mHealth.

Beyond collaboration with corporates, it would also be vital to actively engage with government IT departments to gain further understanding of any current or potential eHealth and mHealth strategies employed. Equally important is the use of unique identification (ID) and health data standards (ie. computer protocols that allow health information to be extracted from one system and transported to another) to enable interoperability between systems. Unique IDs (such as National IDs) are important in tracking the same person across multiple health departments and/or other government services.

Future mHealth programmes should draw on lessons learnt from HAI's pilot programme *Liga Inan* which is supported by Catalpa International's web-based platform. Several other initiatives have also set a good precedent. In 2012 the Alola Foundation, a Timorese NGO that aims to improve the lives of women and children, provided mobile phones to community volunteers in Ermera. The phones were pre-loaded with USD 15 credit and volunteers responsible for monitoring pregnant women were encouraged to call their local clinic when the woman started labour in preparation for facility delivery (Brown 2012). A representative from Childfund who participated in the NGO focus group discussion, outlined a similar project they were negotiating in which health volunteers would be provided with phones to better monitor pregnant mothers. Despite these promising signs, however, Timor-Leste is not yet at a tipping point whereby mHealth would necessarily be quickly adopted. The introduction of mHealth interventions must be aligned to broader health system strengthening and be multi-phased, involving substantial awareness-raising activities at both community level and with health professionals.

4) Engagement of the private sector

Several potential partners from the private sector were identified to enhance child survival activities at both national and local levels. First, the dominant telecom company Timor Telecom, who have majority market share and good network coverage across the country. Their partnership would be required for the effective roll-out of any mHealth intervention at scale and they could provide valuable promotional opportunities raising awareness of key health messages through positive marketing. As discussed, Timor Telecom already use promotional text messages and similar methods of push-notification for health messaging should be explored. In the past, mHealth initiatives have also had success in engaging smaller and less-well known companies, as businesses that are invested in expanding their profiles may have more of a stake in helping to achieve mHealth goals and reaching a wider audience base (Mechael 2009). In this respect, Telemor and, in Oecusse, Telcomcel may also be relevant partners. As the preferred partner of HAI in the implementation of their pilot mHealth programme *Liga Inan*, Catalpa International should also be considered a potential private sector partner as they have experience in the specialised area of using technology as an agent for change (Catalpa International 2013). Similarly, collaborating with HAI is an obvious link for integrating future mHealth initiatives and building on their established platform.

Aside from exploring partnerships with the telcos to provide mHealth support (eg. SMS data services), it may also be valuable to engage with them to share call detail records (CDR) of subscribers in the target areas (although there may be potential date protection and other regulatory issues to consider). This would facilitate a better understanding of mobility patterns (useful for modelling the spread of disease or disaster affected populations), social interaction (the identification of geographical distribution of social connections in order to develop demographic profiles by age and sex to identify behavioural patterns) and economic activities (estimating average household incomes of anonymous subscribers). CDRs are automatically generated by mobile network carriers and capture telecom details such as latitude, longitude, duration of call, number originating the call, number called and name (encrypted for privacy).

In terms of partnering with a national media organisation, Radio-Televisão Timor-Leste was the most frequently cited media outlet during the technology survey and was specifically mentioned as the best placement for health programming by multiple caregivers. In order to reach the largest number of primary caregivers, health programming should be routinely aired at a set time and date so that planned (rather than opportunistic) viewing can be arranged. Given this, it would be important to develop a medium- to long-term plan with a broadcaster to strategise on when to air target messages. The connection of radio and television under one national outlet may also facilitate simultaneous or mutually supportive streams of communication to be aired through multiple channels.

5) Key advocacy issues

Using the UNICEF questionnaire (see Appendix 5) as a base, representatives from the Ministry of Health, UNICEF country office and the NGOs Childfund, CARE and HAI were asked to provide their views on key advocacy issues through which to elevate the priority of and resources for reducing childhood morbidity and mortality due to pneumonia, diarrhoeal disease and newborn complications. Their responses were clustered around five main themes.

Policy and strategy

Stakeholders identified seven thematic areas that present key challenges to equitable healthcare for women and children in Timor-Leste:

- Poor road conditions
- Child malnutrition
- Persistent cultural customs
- Poorly trained / poorly distributed workforce
- Low community awareness of health information
- Low socio-economic status of communities most in need of health services
- Lack of consistent and standardised policies

The first six themes have been discussed at length. In relation to the last point, the lack of consistent and standardised policies, a number of additional issues were raised during consultation with stakeholders.

First, Timor has yet to implement a breastfeeding policy or apply a code for enforcing the sale of breast milk substitutes. Given that 40% of food commodities in Timor are imported stakeholders highlighted the lack of governmental procurement policies in relation to milk substitutes.

Secondly, the need to match demand for healthcare with the reliable and realistic supply of services was emphasised. Stakeholders suggested that mothers were being told to give birth at health facilities, yet health facilities were closed at night and at weekends, did not always have sufficient beds and lacked human resources. Similarly, households were being instructed to use latrines and follow hygienic practices, but some communities did not have a sufficient water source to operate a latrine. Stakeholders concluded that appropriate infrastructure must be put in place before expecting caregivers to adopt best practices.

According to the Ministry of Health, plans commit them to equip all *sucos* with a health post staffed by doctors, nurses, midwives, technicians and with an ambulance. If and when this plan is realised, many of the access barriers cited in this research are likely to be addressed. The government must be supported to accelerate their efforts towards achieving this target and ensure that local community leaders are cognisant of the *suco* development plans.

Planning, management and coordination

UNICEF provides technical support to the Ministry of Health to assist with planning and development and raising community awareness through multiple interventions. Outside the Ministry of Health, however, there is little coordination or collaboration with other areas of government. It was recommended that the Ministry of Education be involved in the design and implementation of health education programmes for school children; the Ministry of Agriculture be involved in addressing nutritional programme objectives; and the Ministry of Transportation should facilitate increased access for rural communities in need. Rural development plans should be better integrated and issues such as paving village lanes (thereby reducing dust and contamination, increasing accessibility and improving local economies) should be prioritised.

Community-wide sanitation (CWS) remains a major challenge in Timor-Leste and engagement in related activities remains low. UNICEF and the Ministry of Health are the main institutions advocating the CWS agenda, and with only a small number of NGOs engaged in related activities, there is urgent need for improved planning, management and coordination across the sector.

In addition, stakeholders commented that capacity within the Ministry of Health had been hampered as many senior officials had been relocated during recent political reshuffles. This resulted in the loss of technical and operational experience and institutional memory. The need for continued capacity building at the Ministry of Health was emphasised.

Human resources

The lack of human resources for health in terms of trained health professionals and their distribution was highlighted. Stakeholders discussed the limited number of trained midwives as a primary contributor to poor outcomes for newborns. Changes to the structure of the Timor health system have resulted in decentralisation of resources, with increased investment in rural health posts. This was regarded by all stakeholders to be a positive development, but more properly staffed health posts were required to achieve adequate coverage. It was suggested that when a midwife was present at a health post, an average of nine to ten facility-based deliveries took place per month, but when a midwife was not present, the rate of home-deliveries without skilled attendance increased. Measures that ensure delivery care and emergency services are offered 24 hours a day, seven days a week in all health facilities should be put in place. The target as expressed in the government's health strategy is for two midwives to be deployed to each health post, yet many health posts currently lack even one, and for those midwives already in post, many lack the training and skills to manage emergency situations. The shortage of Timorese midwives represents the largest gap in the country's health workforce, although there is also a striking shortfall in the number of qualified doctors, particularly those prepared to work in rural areas. As part of a bilateral agreement between Timor-Leste and Cuba, there is an increasing number of Timorese medical students in Cuba. Some doctors return to complete their government service and are posted to rural communities, but not in sufficient number to achieve the goal of one doctor for every health post and one health post per *suco* (Dawson et al. 2011; Asante et al. 2011).

In regards to training deficiencies among those healthcare workers who currently serve in sub-district and health post positions, poor interpersonal communication skills between doctors and patients were cited as a major concern. This was particularly troubling given that rural health workers (doctors, nurses, midwives) are the frontline providers and, at least in theory, are the primary agents for behaviour change. As a key source of health information, there needs to be sustained dialogue between health workers and the communities they serve, and stakeholders concluded that this was not the case in many districts.

Supply chain management

Major gaps exist in the distribution of medicines and result in significant and frequent stock-outs. Essential drugs, including vaccines, are procured and distributed by the government, although some malnutrition and micronutrients are supplied differently. *Service Autonomo de Medicamentos e Equipamentos de Saude* (SAMES) is the supply chain management system used across Timor-Leste and is seen to be largely effective. The root cause of clinic stock-outs is thought to be failure by local health workers to appropriately manage their stock, anticipate shortages and request or re-order supplies in a timely fashion. Vaccine procurement and distribution has also been problematic in recent years, since Singapore Airlines stopped transporting the polio vaccine in 2012. As a result, polio vaccines for Timor now transit through Indonesia, a less efficient procedure with respect to both time and finances.

When a facility has run out of stock, it can take an extended period (from several days to several weeks) for the system to be refreshed. Before SAMES can initiate re-supply, the only stop-gap available is for the clinic to write a letter to the district office requesting money to purchase relief supplies, and wait for an official

stamped letter granting permission to be returned. Internet-based technologies are not widely used as a means of government communication or with regards to procurement, and as a representative from UNICEF explained, 'To *get anything accomplished in Timor you have to write a letter, then you have to get the letter signed, and then you have to get the letter stamped…paperwork causes a long delay*'. Such problems in supply chain management are further exacerbated in Oecusse because of its geographic isolation from the rest of the country.

Political advocacy

Finally and significantly, political commitment to address preventable child deaths in Timor-Leste is needed at all levels. Communities invest great political capital in their village chiefs and sub-chiefs, and in local religious leaders. As trusted officials with reach and influence across their communities, these figureheads must be consulted and actively involved in the design and implementation of health initiatives. Village chiefs in particular are seen to take great pride in their position, and the sustainability, impact and positive outcome of any intervention is dramatically increased through their support and advocacy.

Stakeholders emphasised that amongst high-ranking political leaders in Timor-Leste there is recognition that the health system requires ongoing reform. The Minister of Health believes in health 'as an open vision', and an integral part of the nation's development. Targets and strategies have been developed and positive momentum needs to continue for the government to increase budget allocations for future healthcare programming. In working collaboratively with the Ministry of Health to support their policies and interventions, agencies such as UNICEF have an important role to play in strengthening the health system in Timor-Leste.

Mother and children, Railaco, Ermera

Appendix 1 – Map of Timor-Leste

http://upload.wikimedia.org/wikipedia/commons/7/7d/Un-timor-leste.png

Appendix 2 – Research schedule

Date	Activity
15 October	Arrive in Timor
16 October	Briefing with Ministry of Health/UNICEF Timor-Leste
17 October	Travel to Baucau/Fieldwork Day 1 Baucau (Vemasse)
18 October	Fieldwork Day 2 Baucau (Venilale)
19 October	Fieldwork Day 3 Baucau (Baucau Hospital)
20 October	Fieldwork Day 4 Baucau (Vemasse)/Travel Baucau to Ermera
21 October	Fieldwork Day 1 Ermera (Railaco)
22 October	Fieldwork Day 2 Ermera (Ermera Lama)
23 October	Fieldwork Day 3 Ermera (Gleno)/Travel Ermera to Dili
24 October	Travel Dili to Oecusse
25 October	Fieldwork Day 1 Oecusse (Pante Makasar)
26 October	Fieldwork Day 2 Oecusse (Passabe)
27 October	Fieldwork Day 3 Oecusse (Oesilo)
28 October	Travel Oecusse to Dili
29 October	Meeting with Ministry of Health/UNICEF Timor-Leste/NGOs
30 October	Preparation for de-briefing
31 October	Roundtable workshop at Ministry of Health to share preliminary findings
1 November	Preparation of initial report
2 November	Depart Timor

Appendix 3 – Research tools

Selection of research tools.

Topic guide

Pneumonia, diarrhoea and newborn complications (P, D and NC)
Language used to describe illness/newborn complications
Local theories of causation
Recognition of illness
Preventative measures/prevention strategies
Perception of risk/danger

Care and treatment-seeking behaviour for P, D and NC (including timing and frequency)
Response to illness/newborn complications
Previous experiences (case study)
Treatment strategies/treatment sought (including gender; eg. role of husband)

Modes of healthcare (including perception of service quality)
Biomedical/local/traditional
Relations with healthcare providers (historical, contemporary)
Non-medical impact of seeking different modes of healthcare

Location of healthcare
Distance
Time/Season
Terrain/Traffic
Transport/Access

Household and community
Socio-cultural norms (encourage, discourage behaviour)
Household (priorities and negotiation)
Social relationships, decision-making continuum and agency to act (including gender)
Role of religious and spiritual beliefs, and local custom

Financial
Costs (direct and indirect, eg. time poverty)

Level of (biomedical) knowledge
Health education exposure
Information about services available (demand side)

Local solutions

Behaviour and change
Divergence between theory and practice (eg. know what should do, but doesn't – why?)
Triggers and processes of change in health beliefs and practices (eg. positive deviants identified?)

Technology
Access to mobile phone (including gender)

Interview framework

Primary caregivers with newborns and/or child(ren) under five years experiencing or having recently experienced pneumonia, diarrhoea and/or newborn complications

- Age
- Relationship to child
- Marital status
- Number of children in care
- Age of children
- Gender of children

Do children go to school
Did carer go to school
Does family (paternal, maternal) live near
Religion
Employment
General income range

Q1

What are the main child health problems in your community? Pregnancy and birth related problems?
Do many young children (under 5) die in this area? Delivering mothers and newborns?
What do they die from?

Q2

What do you call pneumonia in your community? What does pneumonia do?
What causes pneumonia and what are the symptoms? Short or long duration?
How do you prevent pneumonia and do you do this?

What do you call diarrhoea in your community? What does diarrhoea do?
What causes diarrhoea and what are the symptoms? Short or long duration?
How do you prevent diarrhoea and do you do this?
Where does your family get water from? Do you drink it directly from the source?
Where does your family (adults and children) go to the toilet? (If in the bush, do you leave it?)
Is it more appropriate to leave child faeces in the open or discard? Why?
Does your family wash their hands? With water only? With soap? When (before dinner, after toilet)?

What are common complications that can result from birth?
What causes complications and what are the symptoms/danger signs?
How do you prevent complications and do you do this?

Why do you think your child's pneumonia/diarrhoea/birth complications started when it did?

Q3

For child illness, do you use traditional medicine/home remedies?
What for? How do you prepare? Where do you get the herbs? Who showed you how to use them?
What are the hoped for results from this treatment?
Does your family use a traditional doctor/spiritual healer for child illness?
What are the hoped for results from this treatment? Do you have to pay? How much?
For birth assistance, do you use traditional birth attendants/midwives/relatives?
What are the hoped for results from this treatment? Do you have to pay? How much? How do you contact when close to delivery? Where does delivery take place? Does anyone else assist?

Do you sometimes go to the health centre for child illness? Antenatal (pregnancy) care/birth assistance?
What are the hoped for results from this treatment?
How far is the health centre from your place? How do you get there?
What cost is incurred to visit the health centre and obtain medicine/care?
What is your opinion about the quality of the services provided by health centre? Do you have to wait?
Do you sometimes use the chemist for child illness? Pregnancy or birth related medicine?
Why do you use the chemist (instead of the health centre?)
How far is the chemist from your place? How do you get there?
What cost is incurred to visit the chemist and obtain medicine?

Q4
When a child is ill, who do you tell? If you are experiencing pregnancy complications, who do you tell?
In the past (1, 3, 6 months) did you talk to anyone about child's illness/birth? With whom?
What kind of help does your husband / family provide to you when a child is ill? What kind of help does your husband / family provide to you when you are preparing for birth?
Who makes the decision to treat the child? Seek birth assistance?
Do you feel capable of taking care of your child when ill/yourself when pregnant and preparing for birth?

Q5
What cultural beliefs influence child illness/birth and treatment seeking in your community?

Q6
How often is your child ill? How often have you experienced complications related to birth?
How often do you get treatment for your child? Seek assistance for pregnancy complications/birth?
When did you last visit the health centre because of child illness? For birth assistance? (Elicit narrative)

Q7
Of the two child illnesses and birth complications, which is the most dangerous for children in your opinion?
What do you fear most about this illness/complication?
Of the two child illnesses and birth complications, which are you most likely to visit a health centre for?

Q8
Where do you get your information about child illness/birth preparedness?
What child survival information, education and communication activities are targeted at mothers?
What measures should be taken to improve the community's knowledge about child illness/birth preparedness?

Q9
What are the main challenges your family faces in going to the health centre or accessing treatment for child illness? Accessing antenatal care or birth assistance?
What are the reasons that some families do not take their child for treatment if they are ill? Pregnant women do not visit healthcare facility for antenatal care and birth assistance?
Does the cost of accessing treatment sometimes prevent you taking the child/yourself?
Does lack of time in daily routine for accessing treatment sometimes prevent you taking the child/yourself?

Q10
What are the solutions to these challenges / barriers?
What can be done to improve the health of children/mothers in this area?

Q12
Do you have a mobile phone for your personal use?
Does any member of your family have a mobile phone? Who is most often in possession of the phone?
Have you ever made/received a health related phone call or text?

Focus group framework

Mothers / fathers of newborns and/or child(ren) under five years experiencing or having recently experienced pneumonia, diarrhoea and/or newborn complications

Q1

What are the main child health problems in your community? Pregnancy and birth related problems?
Do many young children (under 5) die in this area? Delivering mothers and newborns?
What do they die from?

Q2

What causes pneumonia and what are the symptoms? What does pneumonia do?
How do you prevent pneumonia and do you do this?

What causes diarrhoea and what are the symptoms? What does diarrhoea do?
How do you prevent diarrhoea and do you do this?

What causes birth complications and what are the symptoms/danger signs? What does this do?
How do you prevent birth complications and do you do this?

Q3

For child illness, do you/your wife use traditional medicine / home remedies? What are the hoped for results from this treatment?
Does your family use a traditional doctor / spiritual healer for child illness? What are the hoped for results from this treatment?

For birth assistance, do you/your wife use traditional birth attendants/ midwives/ relatives? What are the hoped for results from this treatment?

Do you/ your family sometimes go to the health centre for child illness? Antenatal (pregnancy) care/ birth assistance? What are the hoped for results from this treatment?
How far is the health centre from your place?
What is your opinion about the quality of the services provided by the health centre?

Do you sometimes use the chemist for child illness? Pregnancy or birth related medicine?
Why would you use the chemist (instead of the health centre?)

Q4

What kind of help does your family provide/do you provide your wife when a child is ill? During pregnancy and birth?

Q5

What cultural beliefs influence child illness/birth and treatment seeking in your community?

Q6

What role should mothers/fathers play to prevent children getting pneumonia, diarrhoea and experiencing newborn complications?

What role should mothers/fathers play to ensure children and delivering mothers access treatment quickly and easily?
What role should mothers/fathers play to create awareness about childhood illness/birth preparedness?
Who makes the decision to seek treatment for child illness? Birth assistance?
Do you feel you are/your wife is capable of taking care of child when ill? Of yourself/herself during pregnancy and birth?

Where do you get information about child illness/birth preparedness?
Are there any child survival information, education and communication activities targeted at mothers/fathers?
What measures should be taken to improve mothers'/fathers' knowledge about child illness/birth preparedness?

Q7
What are the main challenges your family faces in going to the health centre or accessing treatment for child illness? Accessing antenatal care and birth assistance?
What are the reasons that some families do not take their child for treatment if they are ill? Pregnant mother for antenatal care and birth assistance?
Does the cost of accessing treatment sometimes prevent taking the child/mother?
Does lack of time in daily routine for accessing treatment sometimes prevent taking the child/mother?

Q8
What are the solutions to these challenges / barriers?
What can be done to improve the health of children and mothers in this area?

Q9
Do you have a mobile phone for your personal use?
Does any member of your family have a mobile phone? Who is most often in possession of the phone?

Focus group framework

Community leaders / health professionals / TBAs treating newborns and/or children under five years of age experiencing or having recently experienced pneumonia, diarrhoea and/or newborn complications

Q1

What are the main child health problems in your community? Pregnancy and birth related problems?
Do many young children (under 5) die in this area? Delivering mothers and newborns?
What do they die from?

Q2

What causes pneumonia and what are the symptoms? What does pneumonia do?
How do you prevent pneumonia and do you do this?

What causes diarrhoea and what are the symptoms? What does diarrhoea do?
How do you prevent diarrhoea and do you do this?

What causes birth complications and what are the symptoms/danger signs? What does this do?
How do you prevent birth complications and do you do this?

Q3

Regarding delivery, what specific activities should health care workers do for the mother and newborn immediately after birth? Is there a specific order for these activities to be performed? Why?
When should the newborn be dried? Contact with mother initiated?
When should the cord be clamped and cut? How?
Should breastfeeding be initiated with a newborn? When?
What are some barriers that may prevent adopting these newborn practices?

Q4

For child illness, do some families use traditional medicine / home remedies? What are the hoped for results from this treatment?
Do some families use a traditional doctor / spiritual healer for child illness? What are the hoped for results from this treatment?

For birth assistance, do some families use traditional birth attendants/ midwives/ relatives? What are the hoped for results from this treatment?

Do some families go to the health centre for child illness? Antenatal (pregnancy) care/ birth assistance?
What are the hoped for results from this treatment?
What is your opinion about the quality of the services provided by the health centre?

Do some families use the chemist for child illness? Pregnancy or birth related medicine?
Why do they use the chemist (instead of the health centre?)

Q5

What kind of help do husbands / family provide to mothers when a child is ill? During pregnancy and birth?

Q6

What cultural beliefs influence child illness/birth and treatment seeking in this community?

Q7

Where do the community learn about child illness? Antenatal care and birth preparedness?
What child survival information, education and communication activities are targeted at mothers/fathers?
What measures should be taken to improve the community's knowledge about child illness? Antenatal care and birth preparedness?

Q8
What activities do health workers undertake in the community?
What challenges do health workers face doing their work in the community?
Do you get support from the health centre, the government, the community?
Do you feel capable of taking care of ill children/pregnant mothers given the current available resources?

Q9
What are the main challenges families in this community face in going to the health centre or accessing treatment for child illness? Accessing antenatal care or birth assistance?
What are the reasons that some families do not take their child for treatment if they are ill? Pregnant mother for antenatal care or birth assistance?
Does the cost of accessing treatment sometimes prevent families from taking the child/mother?
Does lack of time in daily routine for accessing treatment sometimes prevent taking the child/mother?

Q10
What are the solutions to these challenges / barriers?
What can be done to improve the health of children and mothers in this area?

Q12
Do you have a mobile phone for your personal use?
Do you use this phone to communicate with families? With health care facility?

Technology survey
Primary caregivers of children under five years

Date:	Name of Interviewer:	Location: district/sub-district/village

- Age
- Relationship to child
- Marital status
- Number of children in care
- Age of children
- Gender of children

Do children go to school
Did carer go to school
Does family (paternal, maternal) live near
Religion
Employment
General income range

Other technology
1a. Do you listen to the radio?
b. How often? [Not at all, Less than once a week, Once a week, Every day]
c. What radio station(s) do you listen to most often?
d. What type of radio program do you like the most?
e. What types of radio program do you like the least?
f. When do you usually listen to the radio (Day, Time)?
g. On average, how many hours per day do you listen to the radio?

2a. Do you watch television?
b. How often? [Not at all, Less than once a week, Once a week, Every day]
c. What television channel(s) do you watch most often?
d. What type of TV program do you like the most?
e. What type of TV program do you like the least?
f. When do you usually watch TV (Day, Time)?
g. On average, how many hours per day do you watch television?

3a. Do you use a computer with Internet access?
b. How often? [Not at all, Less than once a week, Once a week, Every day]
c. For what purpose do you use the Internet?
d. When do you usually use the Internet (Day, Time)?
e. On average, how many hours per day do you use the Internet?

Mobile technology
4a. Do you have a mobile phone for your personal use? [If no, skip to Question 9]
b. How often is this phone charged/functional? [Not at all, Less than once a week, Once a week, Every day]
c. Does the phone currently have credit and able to make a call?

5a. Is this phone capable of sending and receiving phone calls?
b. Do you make or receive calls?
c. Who do you frequently call or receive calls from?

6a. Is this phone capable of sending and receiving text messages?
b. Can you read text messages from the phone?
c. Do you make or receive text messages?
d. Who do you frequently text or receive texts from?

7a. How is the network reception in your area? [No reception, Not very good, Good]
b. Can you make or receive a phone call using this phone from inside your home?

c. Is there another location where cell reception is good/better than within your home? Where?

8. What phone company provides service for this phone?

9. Could you list the persons who you are closest to who have a mobile phone and tell me how you are related to them [husband, mother-in-law, friend, etc.]? If your phone was out of order, under what circumstance would you go to these persons to borrow their phone?

Name*	**Relationship**	**Borrow phone?**
a_____	_____	**f** Never Emergency Occasionally Anytime
b_____	_____	**g** Never Emergency Occasionally Anytime
c_____	_____	**h** Never Emergency Occasionally Anytime
d_____	_____	**i** Never Emergency Occasionally Anytime
e_____	_____	**j** Never Emergency Occasionally Anytime

10. Please describe the relationship ties between persons listed above. Note: The grid will only be filled completely if interviewee listed 5 names. [**VC** = very close; **C** = close; **S** = strangers]

	Relationship 9b	Relationship 9c	Relationship 9d	Relationship 9e
Relationship 9a				
Relationship 9b				
Relationship 9c				
Relationship 9d				

*Only record initials or first name. Names will not be used in data analysis or the final report.

Appendix 4 – Consent forms

English language version

UNICEF / Anthrologica

Formative research on reducing preventable child deaths from pneumonia, diarrhoea, and newborn complications in Mongolia and Timor-Leste

Background to the study

Pneumonia and newborn complications are the leading causes of child death in Mongolia, whilst diarrhoea, pneumonia and newborn conditions cause the highest number of child deaths in Timor-Leste. UNICEF is supporting the countries to develop integrated programming strategies to focus on the three priority issues in an interrelated fashion. UNICEF has therefore commissioned Anthrologica to conduct formative research to inform programme design and communication for development strategies on reducing preventable child deaths from pneumonia, diarrhoea and newborn complications in Mongolia and Timor-Leste.

Objective of the study

The objective of this study is to learn from caregivers in Mongolia and Timor-Leste. We are interested in:

- Your perceptions and experiences of pneumonia, diarrhoea and newborn complications
- Your treatment-seeking behaviour for pneumonia, diarrhoea and newborn complications
- The barriers, difficulties and challenges you face in accessing treatment for these illnesses
- Your ideas about solutions to these challenges, ways in which the barriers can be overcome, and what would need to happen for better and more timely access to treatment for these illnesses.

Interview/Focus Groups

For this purpose, we would like to talk to you about matters relating to pneumonia, diarrhoea, and newborn complications in children. The informal interview/focus groups will last for approximately one hour. You have the right to withdraw from the discussion at any time without reason.

We will ensure that your information, opinions and experiences are kept confidential and will only be used for the purpose of the study outlined. We will not use your name. You may ask any questions related to the study and we will answer these questions to your satisfaction.

During our discussion we will make an audio recording for our records. This will be destroyed at the end of the study. We may also take a number of photographs of you. These will be used for the purpose of the current study and may be included in academic publications and other material for UNICEF and Anthrologica. If your photograph is published, you shall not be identified by name and the usual confidential process shall be followed.

In regard to collecting information for this study we would greatly appreciate your help and therefore seek your consent and cooperation.

INFORMED CONSENT

I have been informed in detail about the purpose and nature of this study.
I have received satisfactory answers to all my questions relating to this study.
I have decided that I will participate willingly and can withdraw at any time for any reason.
I give my informed consent to participate in this study and have my photograph taken as part of the study.

_____	_____	_____
Name of Participant	**Signature**	**Date**

_____	_____	_____
Name of Witness	**Signature**	**Date**

As a witness of this letter, I ensure that I have the above information has been accurately conveyed to the participant. I also ensure that they have decided to participate in this study freely and willingly.

Tetun language version

UNICEF / Anthrologica

Peskiza Formativu kona ba redusaun ba mortalidade labarik ne'ebe preventavel husi pneumonia, diareia, no komplikasaun ba kosok oan iha Mongolia no Timor-Leste

Kontestu ba estudu

Pneumonia ho komplikasaun ba kosok-oan nukar kauza prinsipal ba labarik mate iha Mongolia, nune'e mos diareia, pneumonia no kondisaun ba kosok-oan nudar kauza ba mortalidade kosok-oan ne'ebe aas iha Timor-Leste. UNICEF suporta hela nasaun ne'e atu dezenvolve estratejía programa integradu hodi foka liu ba asuntu prioridade tolu iha maneira ne'ebe interligadu. Tanba ne'e mak UNICEF hatudu Anthrologica atu hala'o peskiza formativu hodi influensía dezeño programa no komunikasaun hodi dezenvolve estratejia kona ba redusaun ba mortalidade labarik ne'ebe preventavel husi pneumonia, diareia no komplikasaun ba kosok-aon iha Mongolia no Timor-Leste.

Objetivu husi estudu

Objetivu husi estudu ida ne'e maka atu aprende husi sira ne'ebe maka tau matan (ba labarik) iha Mongolia no Timor-Leste. Ami haree liu ba:

- Ita nia persepsaun no esperiensia kona ba pneumonia, diareia no komplikasaun ba kosok-oan
- Ita nia hahalok hodi buka tratamentu ba pneumonia, diareia no komplikasaun ba kosok oan
- Bareira/ satan, difikuldade no dezafiu hirak ne'ebe ita hasoru hodi hetan asesu tratamentu ba moras hirak ne'e
- Ita nia ideia ba solusaun husi dezafiu sira ne'e, dalan atu rezolve bareira/ satan hirak ne'e, no saida mak ita hakarak atu akontense hodi tratamentu bele diak liu no tempu atu asesu ba moras hirak ne'e.

Entrevista/Grupu Fokus

Ba intensaun ida ne'e, ami hakarak koalia ho ita kona ba buat hirak ne'ebe iha relasaun ho pneumonia, diareia, no komplikasaun kosok-oan iha labarik sira. Entrevista informal/ grupu fokus sei hotu iha oras ida hanesan ne'e nia laran. Ita iha direitu atu dada-an/ retira husi diskusaun la ho razaun iha tempu ne'ebe deit.

Ami sei asegura katak ita nia informasaun, opiniaun no esperiensia sei rai ho konfidensialidade no sei uza deit ba intensaun husi estudu. Ami sei la uza ita nia naran. Ita bele husu pergunta relasiona ho estudu no ami sei hatán pergunta hirak ne'e tuir ita nia hakarak.

Ami sei halo gravasaun ba ami nia arkivu durante ita nia diskusaun. Ida ne'e sei destroi bainhira estudu hotu. Ami mos sei hasai ita nia fotografia balu. Buat hirak ne'e sei uza ba objetivu husi estudu ida ne'e no sei bele inkliu iha publikasaun akadémiku no material seluk ba UNICEF no Anthrologica. Karik ita nia fotografia publika, maka ita sei la indentifikadu husi naran no sei halo tuir prosesu konfidensialidade bai-bain.

Relasiona ho kolesaun ba informasaun iha estudu ida ne'e ami hakarak fo apresiasaun bot ba ita nia ajuda no tanba ne'e duni maka ami presiza ita nia aprovasaun no kooperasaun.

APROVASAUN ANTES

Hau hetan ona kunyesimentu antes ho detallo kona ba intensaun no natureza husi estudu ida ne'e.
Hau simu ona responsta ne'ebe satisfas ba hau nia pergunta hirak ne'ebe relasiona ho estudu ne'e.
Hau deside ona katak hau hakarak partisipa no bele dada-an/ retira iha tempu ne'ebe deit no kualker razaun.
Hau fo hau nia aprovasaun atu partisipa iha estudu ne'e no bele hasai hau nia fotografia nudar parte ida husi estudu ne'e.

_____	_____	_____
Partisipante nia naran	**Asinatura**	**Data**

_____	_____	_____
Sasin nia Naran	**Asinatura**	**Data**

Nudar sasin ba karta ida ne'e, hau asegura katak hau hetan ona informasaun ne'ebe temi iha leten ne'e hato'o lolos ona ba partisipante. Hau mos asegura katak sira deside ona ho livre no ho hakarak atu partisipa iha estudu ne'e.

Appendix 5 – UNICEF questionnaire

Review the list of key Pneumonia and Diarrhoea prevention and control and newborn care interventions and decide if the interventions are included in the child and child health related strategies or policies or strategic plans by putting a tick in the corresponding space and write the name of the specific document.

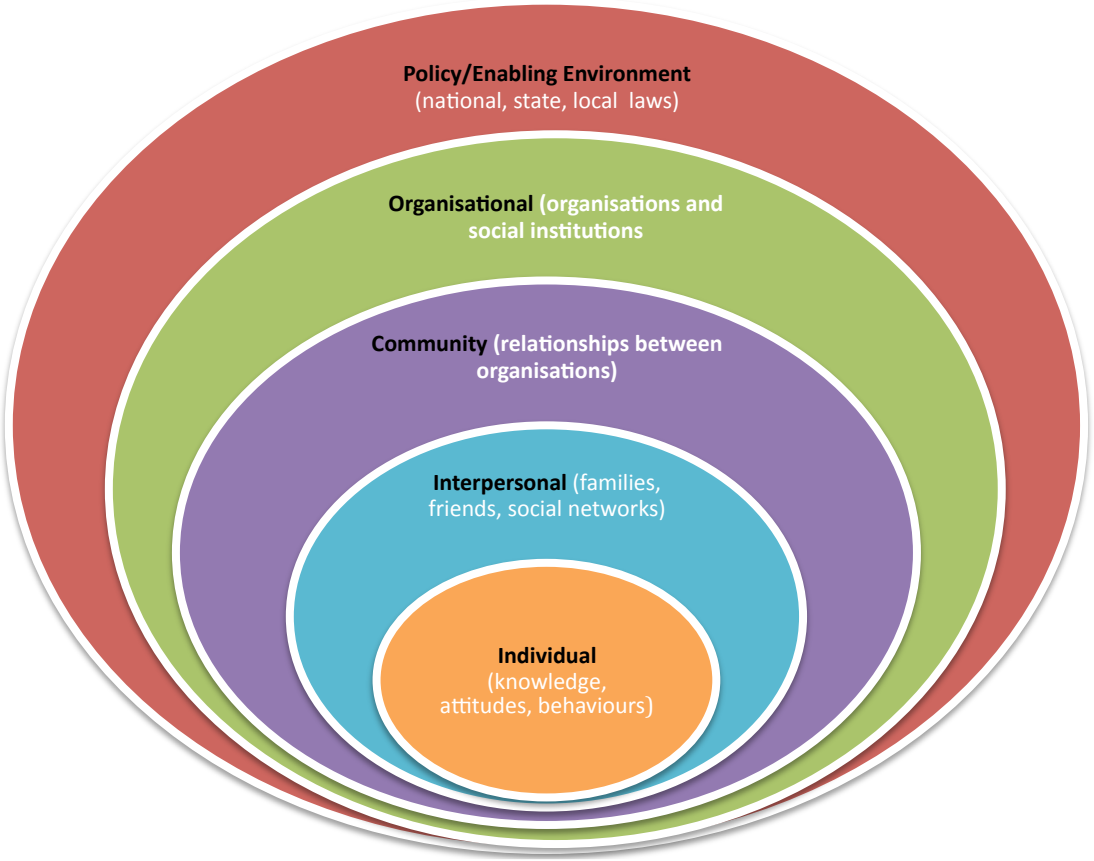
		Maternal and Child Survival strategy /plan	Immunization strategy/cMYP	Nutrition strategy/policy	Malaria strategy	WASH strategy
Interventions to Protect						
1	Exclusive breastfeeding for 6 months					
2	Adequate Nutrition					
3	Treatment & safe storage of household water					
4	Promotion of hand-washing with soap					
5	Community-wide sanitation promotion					
6	Reduce indoor air pollution					
Interventions to Prevent						
7	Measles vaccine					
8	Pertussis vaccine					
9	Spn vaccine					
10	Hib vaccine					
11	Rotavirus vaccine					
12	Prevention of HIV in children					
13	Co-trimoxazole prophylaxis for HIV-infected & exposed children					
14	Vitamin A supplementation of children					
Interventions to Treat						
15	Improved care seeking and demand generation within communities					
16	Health facility case management for pneumonia and diarrhoea					
17	Increasing access to appropriate care through CCM					
18	Oral rehydration therapy (Low Osmolarity ORS)					
19	Zinc treatment to children with diarrhoea					
20	Birth preparedness					

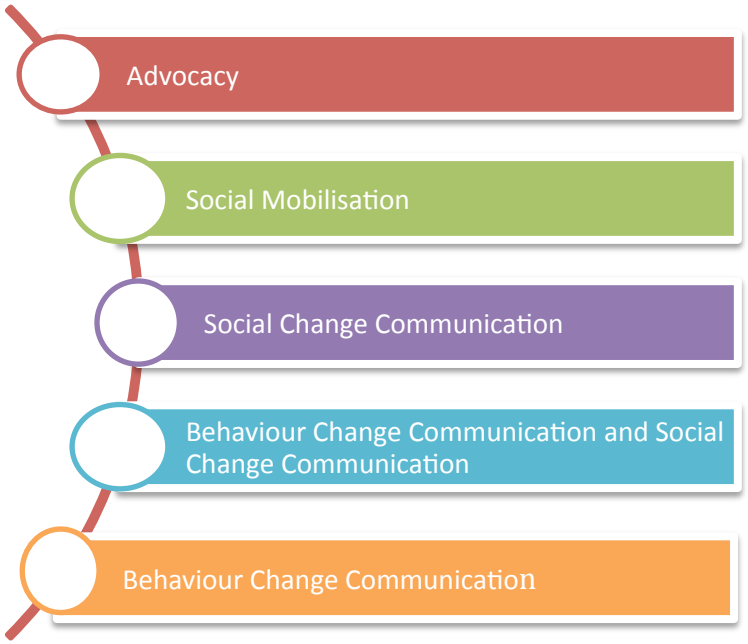
21	Skilled attendance at birth					
22	Improved care of maternal complications					
23	Improved care seeking for newborn complications					
24	Improved essential newborn care					
25	Improved care of sick newborns					

B) What are the key interventions where more action is needed? Highlight specific problems faced by communities and health service providers under the broad following headings.

Activity Area	Problems
Policy/strategy	- Map areas with UNICEF/Ministry of Health colleagues which do not have a supporting policy. - Ask for reasons why it is pending? - What are potential barriers and facilitators?
Planning, management and coordination	- Pneumonia, diarrhoea and newborn care involve many areas of intervention (immunization, skilled birth attendance, essential newborn care, breast feeding, hand hygiene, safe drinking water and good sanitation and reduced levels of air pollution). - How different players are brought together for a concerted response at the moment? - How can coordination be improved?
Human resources	- What are the key human resource gaps (numbers and competencies) and the key issues and possible solutions in relation to: - Immunization - IMCI - Health promotion at community level - Skilled attendance at delivery
Supply Chain Management	- In relation to the following, are there any stock outs for key essential supplies? Are supplies adequate? Are there any distribution/logistic issues? What are the solutions? - Vaccines - ORS - Zinc - Antibiotics - Soap for hand-washing - Running water - Toilet facilities
Advocacy	- How can high-level political commitment be ensured to address these 3 preventable causes of child deaths in your country? - What are the political leaders thinking about these problems? - To whom do they listen? - What will be the right time to highlight the issue? - What is more acceptable way of communicating the message to them? - A policy brief, an individual meeting, a presentation, a political gathering?

Appendix 6 – Social Ecological Model





The social ecological model and corresponding C4D approaches.

(Shefner-Rogers 2013)

Appendix 7 – Technology survey findings

Mobile phone use

Location	Age	Relationship	Income (USD)	Phone credit	Credit charged	Calls made/received	Texts made/received	Service Provider
Baucau (Vemasse)	22	Mother	10-20	No	Everyday	Parents, Uncle	Sibling	Timor Telecom
Baucau (Vemasse)	20	Mother	10-20	No	Weekly	Parents	Relatives	Timor Telecom
Baucau (Vemasse)	23	Mother	300	No	Weekly	Parents	Parents	Timor Telecom
Baucau (Vemasse)	32	Mother	230	Yes	Weekly	Relatives, Friends, Husband	Sibling, Husband	Timor Telecom
Baucau (Venilale)	31	Father	>20	No	Weekly	Relatives	Timor Telecom	Timor Telecom
Baucau (Venilale)	23	Mother	50	No	Everyday	Siblings	Siblings	Timor Telecom
Baucau (Venilale)	36	Mother	270	No	Everyday	Sister-in-Law, Husband	Husband	Timor Telecom, Telemor
Baucau (Venilale)	21	Mother	180	No	Weekly	Husband,Sister-in-Law	Husband,Sister-in-Law	Timor Telecom
Baucau (Venilale)	23	Mother	200-300	No	Weekly	Siblings	Sister	Timor Telecom, Telemor
Baucau (Venilale)	23	Mother	380	No	Weekly	Husband, Sister	Husband, Sister	Timor Telecom
Baucau (Venilale)	32	Mother	170	No	Everyday	Husband, Siblings	Husband, Siblings	Timor Telecom
Baucau Hospital	40	Father	280	Yes	Everyday	Brothers	Brothers	Timor Telecom, Telemor
Baucau Hospital	30	Mother	240	Yes	Weekly	Husband	Husband	Timor Telecom, Telemor
Baucau Hospital	25	Mother	0	No	Everyday	Brothers	Friends	Timor Telecom
Baucau Hospital	39	Mother	0	Yes	Weekly	Parents, Siblings	Parents, Siblings	Timor Telecom
Baucau (Caibada Makasae)	37	Mother	136	Yes	Everyday	Friends	Timor Telecom	Timor Telecom
Baucau (Caibada Makasae)	32	Mother	85	Yes	Weekly	Realtives, Friends	Sub-village Chief, Village council	Timor Telecom
Baucau (Caibada Makasae)	20	Mother	0	No	Weekly	Relatives	Relatives, Friends	Timor Telecom
Baucau (Caibada Makasae)	30	Mother	100	No	Weekly	Siblings	Timor Telecom	Timor Telecom
Baucau (Caibada Makasae)	20	Mother	296	No	Weekly	Husband,Friends	Husband, Friends	Timor Telecom
Baucau (Caibada Makasae)	42	Mother	300	Yes	Weekly	Husband	Husband, Timor Telecom	Timor Telecom
Baucau (Vemasse)	32	Mother	200	Yes	Everyday	Husband	Husband, Siblings	Timor Telecom
Ermera (Railaco)	23	Mother	100	No	Everyday	Husband	Relatives	Timor Telecom, Telemor
Ermera (Railaco)	30	Mother	120	Yes	Weekly	Relatives	Relatives	Timor Telecom
Ermera (Railaco)	22	Mother	0	No	Weekly	Relatives	Relatives	Timor Telecom
Ermera (Railaco)	35	Mother	0	Yes	Weekly	Relatives	Relatives	Timor Telecom, Telemor
Ermera (Railaco)	21	Mother	0	No	Weekly	Parents	Parents	Timor Telecom, Telemor
Ermera (Railaco)	23	Mother	100	No	Everyday	Parents, Relatives	Relatives	Timor Telecom
Ermera (Railaco)	23	Mother	50	No	Weekly	Husband, Relatives	Husband, Relatives	Telemor
Ermera (Railaco)	29	Mother	85	No	> Weekly	Village Chief, Sub-village Chief	Timor Telecom	Timor Telecom
Ermera Lama	24	Mother	0	Yes	Weekly	Relatives	Timor Telecom, Relatives	Timor Telecom, Telemor
Ermera Lama	22	Mother	50	No	Everyday	Siblings	Siblings	Timor Telecom
Ermera (Gleno)	26	Mother	0	Yes	> Weekly	Husband	Husband, Timor Telecom	Timor Telecom
Ermera (Gleno)	25	Mother	60	No	Everyday	Husband	Cousin	Timor Telecom
Ermera (Gleno)	25	Mother	0	No	Everyday	Husband	Husband, Relatives	Timor Telecom
Ermera (Gleno)	23	Mother	200	No	> Weekly	Relatives	Relatives	Timor Telecom

Location	Age	Relationship	Income (USD)	Phone credit	Credit charged	Calls made/received	Texts made/received	Service Provider
Ermera (Gleno)	24	Mother	50	Yes	Everyday	Relatives	Relatives	Timor Telecom
Ermera (Gleno)	34	Adopted Mother	200	Yes	> Weekly	Siblings	Siblings	Timor Telecom, Telemor
Oecusse (Naimeco)	29	Uncle	460	Yes	Everyday	Girlfriend	Girlfriend	Timor Telecom
Oecusse (Naimeco)	21	Uncle	50	No	Everyday	Father, Brother	Father, Brother	Timor Telecom, Telemor
Oecusse (Naimeco)	21	Brother	0	No	Everyday	Parents	Parents	Telemor
Oecusse (Naimeco)	30	Mother	80	Yes	On demand		Do not text	Telemor
Oecusse (Naimeco)	22	Mother	200	Yes	Everyday	Relavtives, Fuel Seller	Relatives	Timor Telecom
Oecusse (Naimeco)	26	Mother	200	Yes	Everyday	Sisiter	Brothers, Sisters	Timor Telecom, Telemor
Oecusse (Naimeco)	26	Mother	70	Yes	Everyday	Brother	Timor Telecom	Timor Telecom
Oecusse (Naimeco)	27	Mother	50	Yes	Everyday	Sisters	Sisters	Timor Telecom
Oecusse (Naimeco)	27	Mother	150	Yes	Everyday	Husband, Sister	Timor Telecom	Timor Telecom
Oecusse (Naimeco)	22	Mother	400	Yes	Everyday	Relatives	Relatives	Timor Telecom
Oecusse (Passabe)	23	Mother	30	Yes	Everyday	Grandmother	Timor Telecom	Timor Telecom, Telemor
Oecusse (Passabe)	24	Mother	140	Yes	Everyday	Sister	Sister	Timor Telecom, Telemor, & Telcomcel
Oecusse (Passabe)	25	Mother	115	Yes	Everyday	Brothers	Sister, Timor Telecom	Timor Telecom
Oecusse (Passabe)	33	Mother	306	Yes	Everyday	Brother	Mother, Brother	Timor Telecom, Telcomcel
Oecusse (Passabe)	25	Mother	166	Yes	Everyday	Uncle	Grandfather	Timor Telecom
Oecusse (Passabe)	33	Mother	100	Yes	Everyday	Son, Brothers	Son	Telemor
Oecusse (Passabe)	24	Mother	160	Yes	Everyday	Relatives, Friends	Friends	Timor Telecom
Oecusse (Passabe)	29	Mother	200	Yes	Everyday	Parents	Relatives, Timor Telecom	Timor Telecom
Oecusse (Passabe)	29	Mother	65	Yes	Everyday	Friends	Friends	Timor Telecom
Oecusse (Passabe)	21	Mother	166	Yes	Everyday	Brothers	Broters, Timor Telecom	Timor Telecom
Oecusse (Passabe)	20	Mother	45	Yes	Everyday	Relatives	Relatives, Telcomcel	Telcomcel
Oecusse (Passabe)	29	Mother	150	No	Everyday	Husband	Do not text	Timor Telecom, Telemor & Telcomcel
Oecusse (Oesilo)	45	Father	50	Yes	On demand	Sister, Son	Relatives, Employer	Timor Telecom
Oecusse (Oesilo)	32	Mother	50	Yes	Everyday	Relatives	Brother, Sister-in-Law	Telemor

Television viewing practices

Location	Age	Relationship	Income (USD)	Viewing frequency	Favorite Channel	Favorite Program	When	Duration
Baucau (Vemasse)	22	Mother	10-20	< Once a week	Compac Disk	Music	Monday-Sunday, 8pm	1 hour
Baucau (Vemasse)	20	Mother	10-20	Everyday	Indosiar	Movies	Monday-Sunday, 8-10pm	2 hours
Baucau (Vemasse)	23	Mother	300	Once a week	Indosiar	Movies	Saturday, 9pm	30 minutes
Baucau (Vemasse)	34	Mother	15	Everyday	TVTL	News	Monday-Sunday, 6-7pm	30 minutes
Baucau (Vemasse)	32	Mother	230	Everyday	TVTL	News	Monday-Saturday, 8pm	30 minutes
Baucau (Vemasse)	57	Grandmother	50	Everyday	TVTL	News	Monday-Sunday, 8pm	30 minutes
Baucau (Venilale)	24	Mother	50	Everyday	TVTL, Indosiar	News, Music	Monday-Sunday, 8pm	2 hours
Baucau (Venilale)	31	Father	<20	Everyday	TVTL	News	Monday-Friday, 8pm	90 minutes
Baucau (Venilale)	45	Grandmother	60	Everyday	TVTL	News	Monday-Friday, 8pm	30 minutes
Baucau (Venilale)	23	Mother	50	Twice a week	Indosiar	Sports	Monday, Saturday, 4am	1 hour
Baucau (Venilale)	36	Mother	270	< Once a week	Indosiar	Movies	Saturday, 8pm	1 hour
Baucau (Venilale)	30	Mother	20	Once a week	TPI, Indosiar	News, Movies	When I have free time	1 hour
Baucau (Venilale)	21	Mother	180	Everyday	TVTL, Indosiar, TPI	News, Movies	Monday-Sunday, 7pm	3 hours
Baucau (Venilale)	23	Mother	380	Once a week	TVTL	News, Music	Friday, 12pm	1 hour
Baucau (Venilale)	32	Mother	170	Once a week	TVTL, Indosiar	News, Music	Anytime, 8pm	30 minutes
Baucau Hospital	40	Father	280	Everyday	TVTL	News	Monday-Friday, 8pm	30 minutes
Baucau Hospital	39	Mother	0	Once a week	TVTL	News	When I have free time, 6pm	30 minutes
Baucau (Caibada Makasae)	37	Mother	136	Sometimes	Indosiar	Movies	Monday-Sunday, 8pm	30-60 minues
Baucau (Caibada Makasae)	32	Mother	85	Everyday	TVTL	News	Monday-Friday, 8pm	30 minutes
Baucau (Caibada Makasae)	20	Mother	296	Everyday	Indosiar	Music	Monday-Sunday, 8pm	1 hour
Baucau (Caibada Makasae)	26	Mother	140	Everyday	TVTL, Other channels	News, Music, Health Programs	Monday-Sunday, 8pm	I hour
Baucau (Caibada Makasae)	42	Mother	300	Everyday	Indosiar, RCTI, TVTL	News, Music, Celebrities	Monday-Sunday, 8pm	1 hour
Baucau (Vemasse)	30	Mother	0	Everyday	TVTL, Indonesian TV	Drama	Monday-Sunday, 7pm	3 hours
Baucau (Vemasse)	30	Mother	0	Rare	TVTL	News	Anytime, 8pm	30 minutes
Baucau (Vemasse)	32	Mother	200	< Once a week	TVTL, Indonesian TV	News, Indonesian movies	Anytime, 8pm	30 minutes
Ermera (Railaco)	29	Mother	500	Everyday	TVTL	News	Monday-Sunday,4-5pm	1 hour
Ermera (Railaco)	23	Mother	100	Everyday	TVTL	News	Monday-Friday, 8pm	1 hour
Ermera (Railaco)	30	Mother	120	Everyday	TVTL	News	Monday-Friday, 8pm	30 minutes
Ermera (Railaco)	22	Mother	0	Sometimes	TVTL	News, Music	When I have free time, 6pm	1-2 hours
Ermera (Railaco)	23	Mother	120	Everyday	TVTL	News	Monday-Saturday, 8pm	1 hour
Ermera (Railaco)	35	Mother	0	Everyday	TVTL	Health Programs	Anytime	1 hour
Ermera (Railaco)	21	Mother	0	< Once a week		Movies	Anytime	10-15 minutes
Ermera (Railaco)	21	Mother	0	< Once a week	TVTL	All programs	Anytime	5 minutes
Ermera (Railaco)	23	Mother	100	Everyday	TVTL	News	Monday-Friday, 7pm	2 hours
Ermera (Railaco)	23	Mother	50	Sometimes	TVTL	News	Anytime, 8pm	30 minutes
Ermera (Railaco)	29	Mother	85	Everyday	TVTL	News	Monday-Saturday, 8pm	1 hour
Ermera Lama	24	Mother	0	Everyday	RCTI, Indosiar, TVTL	Entertainment, Sports	Monday-Saturday, 8pm	2 hours
Ermera Lama	22	Mother	50	Sometimes	TVTL	News (Timorense)	When I have free time	6 minutes
Ermera Lama	30	Mother	0	Sometimes	TVTL	News	When visiting relatives	2 hours
Ermera (Gleno)	26	Mother	0	Everyday	TVTL, Indonesian TV	News, Movies	Monday-Sunday, 7pm	1-2 hours
Ermera (Gleno)	25	Mother	60	Everyday	TVTL	News	Monday-Friday, 8-9pm	20-30 minutes

Location	Age	Relationship	Income (USD)	Viewing frequency	Favorite Channel	Favorite Program	When	Duration
Ermera (Gleno)	25	Mother	0	Everyday	TVTL	News	Monday-Friday, 8pm	1 hour
Ermera (Gleno)	23	Mother	200	Everyday	TVTL, Indosiar	News, Movies	Monday-Saturday, 9pm	1 hour
Ermera (Gleno)	24	Mother	50	Everyday	TVTL	News	Monday-Friday, 8pm	30 minutes
Ermera (Gleno)	34	Adopted Mother	200	Everyday	TVTL, TPI, Indosiar	News, Movies	Monday-Sunday, 8pm	3 hours
Oecusse (Naimeco)	29	Uncle	460	Every day	TVTL	News	Evening, 7:30-11pm	3 hours
Oecusse (Naimeco)	21	Uncle	50	3 times a week	TVTL	Educational programs	Evening, 8-10pm	2 hours
Oecusse (Naimeco)	21	Brother	0	5 times a week	TVTL	Development and Educational programs	Evening, 8-10pm	2 hours
Oecusse (Naimeco)	30	Mother	80	Once a week	TVTL	Sports	Midnight-3am	3 hours
Oecusse (Naimeco)	22	Mother	200	Everyday	Indosiar	Movies	Evening, 8:30-11pm	2 hours 30 minutes
Oecusse (Naimeco)	26	Mother	200	Everyday	Movies	Movies & Music	Evening, 8-9:30pm	90 minutes
Oecusse (Naimeco)	26	Mother	70	3 times a week	TVTL	News	Evening, 8-8:30pm	30 minutes
Oecusse (Naimeco)	27	Mother	50	Everyday	TVTL	News (Timorense)	Evening, 8-10pm	2 hours
Oecusse (Naimeco)	27	Mother	150	Everyday (except when power out)	Any channel	News, Movies	When I have free time	90 minutes
Oecusse (Naimeco)	22	Mother	400	Once a week	TVTL	News, Sports	Evening, 8pm-12am	4 hours
Oecusse (Passabe)	23	Mother	30	Everyday (except when power out)	CD programs	News	Evening,7pm-12am	5 hours
Oecusse (Passabe)	18	Mother	20	Twice a week	CD programs	Music	Evening, 8-12pm	4 hours
Oecusse (Passabe)	24	Mother	140	Everyday (except when power out)	TVTL	News	Evening, 8-9pm	1 hour
Oecusse (Passabe)	25	Mother	115	Twice a week	TVTL	News	Evening, 8-9pm	1 hour
Oecusse (Passabe)	33	Mother	306	Once a week	TVTL, Indonesian TV	Advertisements	Morning, 9-12pm	3 hours
Oecusse (Passabe)	25	Mother	166	3 times a week	TVTL, Indonesian TV	Music, Government programs	Evening, 8-9pm	1 hour
Oecusse (Passabe)	33	Mother	100	Everyday	World TV	News	Evening, 8-9pm	1 hour
Oecusse (Passabe)	24	Mother	160	Twice a week	World TV	News, Movies	Evening, 9-9:30pm	30 minutes
Oecusse (Passabe)	29	Mother	200	Everyday (except when power out)	TVTL, Indonesian TV	"Small letter for God"	Evening, 9-10pm	1 hour
Oecusse (Passabe)	29	Mother	65	Once a week	TVTL	News	Evening, 8-8:30pm	30 minutes
Oecusse (Oesilo)	23	Mother	200	Once a week	TVTL	Movies	Evening, 10am-12pm	2 hours
Oecusse (Oesilo)	23	Mother	50	Once a week	CD programs	N/A		2 hours
Oecusse (Oesilo)	32	Mother	50	Once a week	TVTL, Indonesian TV	All programs	Evening, 9-11pm	2 hours

Radio listening practices

Location	Age	Relationship	Income (USD)	Frequency	Favorite Station	Favorite Program	When	Duration
Baucau (Vemasse)	20	Mother	10-20	Everyday	Radio Maubere	Music	Monday-Sunday, 9pm	2 Hours
Baucau (Vemasse)	34	Mother	15	Less than once a week	RTTL	Music	Everyday, Anytime	< 1 hour
Baucau (Vemasse)	32	Mother	230	Everyday	RTTL	News	Monday-Sunday, 6-8pm	1 hour
Baucau (Vemasse)	57	Grandmother	50	Everyday	Radio Maubere	-	Monday-Sunday	1 hour
Baucau (Venilale)	24	Mother	50	Once a week	Radio Maubere, RTL	News	When I go pass by neighbors' house	30 minutes
Baucau (Venilale)	45	Grandmother	60	Everyday	Radio Maubere	Programs about Timor	Monday-Sunday, 8pm	2 hours
Baucau (Venilale)	23	Mother	50	Once a week	RTTL	Music	Monday-Wednesday, Saturday, 8pm	1 hour
Baucau (Venilale)	36	Mother	270	Once a week	Radio Maubere	Health	Saturday, Anytime	15 minutes
Baucau (Venilale)	30	Mother	20	Less than once a week	Radio Maubere	Music	Anytime, 7am	5 minutes
Baucau Hospital	40	Father	280	Everyday	RTL	News	Monday-Friday, 6am, 12pm	30 minutes
Baucau Hospital	30	Mother	240	Sometimes	Salessian School Radion in Fatumaka	News	Anytime, 6pm	1 hour
Baucau Hospital	39	Mother	0	Sometimes	RTTL	News	Anytime	40-60 minutes
Baucau (Caibada Makasae)	37	Mother	136	Sometimes	RTTL	Zodiac	Monday, Tuesday, 11am	30 minutes
Baucau (Caibada Makasae)	32	Mother	85	Sometimes	RTL	News	Saturday, 7am	30 minutes
Baucau (Caibada Makasae)	20	Mother	0	Everyday	RTL	Music	Monday-Saturday, 7am-Evening	3-4 hours
Baucau (Caibada Makasae)	30	Mother	100	Sometimes	RTL	-	-	-
Baucau (Caibada Makasae)	22	Mother	0	Sometimes	RTL	-	-	-
Baucau (Caibada Makasae)	19	Mother	150	Sometimes	RTL	History	Saturday, 7am	30 minutes
Baucau (Caibada Makasae)	20	Mother	296	Sometimes	Radio Maubere, RTL	Health	Anytime, 4pm	5-30 minutes
Baucau (Caibada Makasae)	42	Mother	300	Sometimes	Radio Maubere, RTL	Interactive dialogue	Anytime, 7am	15 minutes
Baucau (Vemasse)	30	Mother	0	Less than once a week	RTL	-	-	-
Baucau (Vemasse)	32	Mother	200	Everyday	RTL	News	Monday-Sunday, 7am	2 hours
Ermera (Railaco)	29	Mother	500	Sometimes	RTL	News	Monday, Thursday, 4pm	4-5 minutes
Ermera (Railaco)	30	Mother	120	Everyday	RTL	News, Health, Education	Monday-Friday, 12pm, 3pm	30 minutes
Ermera (Railaco)	23	Mother	120	Sometimes	RTL	News	Sunday, 5pm	30 minutes
Ermera (Railaco)	35	Mother	0	Rare	RTL	Health	-	-
Ermera (Railaco)	21	Mother	0	Sometimes	RTL	-	Monday, 8pm	1 hour
Ermera (Railaco)	23	Mother	100	Everyday	RTL, Radio Maubere, Radio Voz	Information about women's rights	Monday-Friday, 8pm	1 hour
Ermera (Railaco)	29	Mother	85	Sometimes	RTL, Rakambia	Music, News	Anytime	1-3 minutes
Ermera Lama	22	Mother	0	Sometimes	RTL	-	Wednesday, Thursday	5 minutes
Ermera Lama	24	Mother	0	Sometimes	RTL	Anything	Monday, Saturday, 8am, 4pm	30 minutes
Ermera Lama	22	Mother	50	Everyday	RTL	News	Monday-Friday, 7am, 4pm	1 hour
Ermera Lama	30	Mother	0	Sometimes	RTL	Health	Saturday, 7pm	4 minutes
Ermera Lama	25	Mother	0	Everyday	RTL, Radio Café	Health	Monday-Friday, 6am	1 hour
Ermera (Gleno)	26	Mother	0	Everyday	RTL	News, Music	Monday-Friday, 8am, 4pm	1 hour
Ermera (Gleno)	25	Mother	60	Everyday	Radio Rakambia, RTL	News, Music	Monday-Sunday, 6am, 2 pm	20 minutes
Ermera (Gleno)	23	Mother	0	Everyday	Radio Maubere	Music	Monday-Saturday, 8am	< 10 minutes
Ermera (Gleno)	23	Mother	200	Once a week	Radi Café	News	Monday, 9pm	2-3 hours
Ermera (Gleno)	24	Mother	50	Everyday	RTL	News	Monday-Friday, 7-10pm	3 hours
Ermera (Gleno)	34	Adopted Mother	200	Sometimes	RTL	News, Music	Monday 8pm	20 minutes
Oecusse (Naimeco)	29	Uncle	460	Everyday	RTTL	Programs about Timor	Evening, 6-7pm	1 hour
Oecusse (Naimeco)	21	Uncle	50	Twice a week	Radio Maubere	Music, Education	Evening, 8-10pm	2 hours

Location	Age	Relationship	Income (USD)	Frequency	Favorite Station	Favorite Program	When	Duration
Oecusse (Naimeco)	21	Brother	0	3 times a week	Radio Maubere	National Development, Education	Evening,9-10pm	1 hour
Oecusse (Naimeco)	26	Mother	200	Twice a month	RTTL	Health, Education	Day, 11-12pm	1 hour
Oecusse (Naimeco)	27	Mother	50	Twice a week	RTTL	Anything	Evening, 8-10pm	2 hours
Oecusse (Naimeco)	22	Mother	400	Everyday	Radio Maubere	News, Music	Daytime	2 hours
Oecusse (Passabe)	29	Mother	200	Once a week	RTTL	Theatre	Evening, 9-10pm	1 hour
Oecusse (Oesilo)	23	Mother	200	Twice a week	Radio Maubere, RTL	Music	When I have free time	1 hour
Oecusse (Oesilo)	23	Mother	50	Once a week	RCAL	News	Evening, 7-8pm	1 hour
Oecusse (Oesilo)	45	Father	50	3 times a week	Radio Maubere, RTL, RCAL	Anything	Anytime	4 hours
Oecusse (Oesilo)	32	Mother	50	Everyday	Radio Maubere, RTL	News	Morning, Evening	4 hours

Internet use

Location	Age	Relationship	Employment	Income (USD)	Frequency	Purpose	When	Duration
Baucau (Caibada Makasae)	20	Mother	Student	296	Twice a week	For school assignment	Saturday or Sunday, 8pm	2 hours
Ermera (Gleno)	24	Mother	IT & English trainer	50	Everyday	Facebook / Information	Monday-Sunday, 9am	2-3 hours
Ermera (Gleno)	34	Adopted Mother	Small business	200	Twice a week			
Oecusse (Naimeco)	29	Uncle	Herders	460	3 times a week	Facebook / Access emails / Find jobs	Anytime	1 hour

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