CHIFA Discussion on Newborn Care #1

16 October to 25 November 2017

What is the size of the problem? What do we know about quality of care at different levels?

SHORT EDIT

Highlights selected/edited by: Samantha Sadoo & Neil Pakenham-Walsh, 3 January 2018

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http://www.hifa.org/projects/newborn-care

Background to the discussion: http://www.hifa.org/news/join-chifa-global-discussion-newborn-care-low-and-middle-income-countries

See also our blog on the Healthy Newborn Network:
https://www.healthynewbornnetwork.org/blog/join-3000-child-health-professionals-140-countries-global-discussion-care-small-sick-newborns-low-middle-income-countries/

Metrics: 128 contributions from 41 contributors in 12 countries (Bangladesh, Canada, Ethiopia, Ghana, India, Kenya, Malawi, Nigeria, Rwanda, South Africa, UK, USA). (For full list, see Long Edit)

1. What is the size of the problem? How many newborns die, where, and why? How many more suffer major morbidity? What are the trends?

Joy Lawn (UK): "Each year 2.7 million newborns die with 98% of these deaths in low and middle income countries, and more than 80% are small, with preterm infants being at greatest risk. Now that 80% of the world's births are in hospitals, more newborn deaths are occurring in hospitals, and over two-thirds of these deaths could be prevented with effective hospital care for small and sick newborns.

Neil Pakenham-Walsh (NPW, UK): Approximately 7 000 newborns die every day with about 1 million dying on the first day and close to 1 million dying within the next 6 days.
- Children who die within the first 28 days of birth suffer from conditions and diseases associated with lack of quality care at birth or skilled care and treatment immediately after birth.
- The main killers of children under 5 in 2016 included preterm birth complications, pneumonia, intrapartum related events, diarrhoea, neonatal sepsis and malaria.

Samantha Sadoo (UK): 2014 Lancet Every Newborn series (paper 3)
- Increased coverage and quality of preconception, antenatal, intrapartum, and postnatal interventions by 2025 could avert 71% of neonatal deaths (1·9 million) and 33% of stillbirths (0·82 million) a year.
- Most (82%) of this effect is attributable to facility-based care which, although more expensive than community-based strategies, improves the likelihood of survival.
- Available interventions can reduce the three most common cause of neonatal mortality—preterm, intrapartum, and infection-related deaths—by 58%, 79%, and 84%, respectively.

Mary Kinney (South Africa): Newborn Numbers on HNN includes the global burden of newborn deaths including when, when and why newborns are dying as well as solutions for preventing deaths and resources available for action on newborn health.
[https://www.healthynewbornnetwork.org/numbers/]

Trends?

Mary Kinney: UNICEF, WHO and other members of the UN Inter-Agency Group for Child Mortality Estimation (IGME) have just released the new child mortality data [http://www.childmortality.org/] for 196 countries. The report [https://data.unicef.org/resources/levels-trends-child-mortality/] has a heavy focus newborn mortality because the data reveal that the rate of newborn deaths is not decreasing as quickly as that of children aged one to five. In 2016, 46% of all under-5 child deaths were among newborns in their first 28 days of life, which has grown from 40 % in 1990.
Judith Robb-McCord (USA): The Preterm Birth/Low Birth Weight Country Profiles developed by USAID's Every Preemie SCALE project for 25 low-income priority countries, has been recently updated. These profiles paint an interesting picture of where risk around preterm birth lies, strengths and gaps in services across the reproductive and maternal health continuum of care, and the enabling environment for the management of preterm birth and early/small babies by country.
http://www.everypreemie.org/country-profiles/

Where?

NPW: 77% of newborn deaths occur in Southern Asia or sub-Saharan Africa. Five countries accounted for half of all newborn deaths: India, Pakistan, Nigeria, the Democratic Republic of the Congo and Ethiopia.
A study in India found that between 2000 and 2015, prematurity or low birthweight mortality rates rose in rural areas (from 13·2 per 1000 livebirths to 17·0 per 1000 livebirths) and in poorer states (from 11·3 per 1000 livebirths to 17·8 per 1000 livebirths), but reduced in urban areas and in richer states. The large and sustained difference in mortality rates between rural and urban areas of India should be a point of concern for other LMICs, especially those with large rural populations.
http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(17)32162-1/fulltext

Samantha Sadoo: At least half of neonatal deaths arise after home births (2005 Lancet Neonatal Survival series).

2. What do we know about quality of care (QOC) in the home, community and primary health centres? What level of care is available for small and/or sick newborns?

What level of care is available?

Claire Keene (UK/Kenya): It seems to be fairly widely accepted that the minimum level of care includes basic care of the newborn and basic neonatal resuscitation, and that the highest level covers intensive care, mechanical ventilation and more specialised services. But how should the care babies receive between these two ends of the spectrum be categorised, and what care should be provided at which level of hospital?

Sue Prullage (Rwanda): I do not think that care should be completely regionalized, with basic facilities referring to central high level facilities. Without a true transport system infants may die before reaching the higher level of care, or arrive in respiratory distress, cold and hypoglycemic. I think a high dependency unit at low level hospitals in rural areas closer to the receiving population would be good, if the staff and doctors are specially trained in neonatal issues. The transport process could be looked at and guidelines written.

Ruth Davidge (South Africa): I agree transporting is a major issue. The things that should be considered 1. Increasing the use of skin to skin during transport, 2. Teaching the S.T.A.B.L.E course developed by neonatal nurse Chris Carlson, aimed at stabilising babies prior to transfer, 3. The use of retrieval teams based at central hospitals that can go and stabilise and return with the baby.

Claire Keene: Explicitly defining levels can help understand what the current capacity of a system is as well as advocate for improvements, and makes planning of resource allocation according to need easier. There are explicit guidelines for specific countries such as the US, UK, Australia, South Africa and India, but it is unclear how these translate to LMICs which have very different ways of organising their health systems.

Lily Kak (USA): USAID and the Every Preemie project team are collaborating with several partners including UNICEF, WHO, Save the Children, to support governments to conduct a multi-country situational analysis of inpatient sick newborn and young infant care (0-60 days). The objective is to describe the national enabling environment for service implementation and quality of inpatient care.

Samantha Sadoo: Standardised measurement of emergency obstetric care has improved tracking and accountability using indicators based on "signal functions", to monitor the availability and use of emergency obstetric care (EmOC) services. However, signal functions to track service readiness to provide inpatient care of small and sick newborns is not consistently defined or routinely tracked. The Every Newborn Action Plan (ENAP) metrics group held an expert focus group in April 2016 that identified 13 core newborn interventions that services should be ready to provide at a basic and advanced inpatient level, and launched an online survey to canvas opinion from healthcare professionals worldwide, with the aim to define signal functions for inpatient care for small and sick newborns (results currently being analysed).

Community/ Traditional birth attendants

Several community-based interventions have achieved impressive results, driving increases in the utilization of maternal and newborn health services, improvements in the quality of care and even reductions in maternal mortality. Involving community members throughout the process of designing, implementing and evaluating maternal and newborn health interventions is critical to the success and sustainability of programs.https://www.mhtf.org/2017/10/19/facilitators-and-barriers-to-engaging-communities-in-maternal-and-newborn-health-programs
https://bmcpregnancychildbirth.biomedcentral.com/articles/10.1186/s12884-017-1443-0

Lily Kak (USA): The question of whether we should train traditional birth attendants to resuscitate newborns was a real dilemma for a global public-private alliance that came together in 2010 with the support of USAID and the American Academy of Pediatrics to roll out Helping Babies Breathe. After much discussion, the alliance made a deliberate decision to focus on improving the capacity and quality of care in health facilities. This meant that our strategy focused on training skilled birth attendants and not traditional birth attendants. With increasing institutional delivery in many countries, closing this quality gap in health facilities is of paramount importance. The issue of training TBAs has long been controversial and an emotional debate; the group decided that it would be more constructive to focus on a non-controversial approach that is likely to have greater impact.

Dayo Ajayi-Obe (UK): In Lagos State Nigeria in 2016, 40% of mothers were delivered by traditional birth attendants. Traditional birth attendants are a heterogeneous group: faith based, auxiliary healthcare workers and traditional spiritualists with no training when it comes to looking after the newborn baby. I advocate that these traditional birth attendants require training in resuscitation and how to safely transfer babies. I know that the drive is for babies to be born within the hospital setting but accessing healthcare can be complex for various reasons.

Kishwar Azad (Bangladesh): It's true that more than 30% of deliveries in the rural areas in Bangladesh still occur at the hands of TBAs. There is no point in ignoring this fact and say we must not train TBAs. Until such a time that all deliveries are conducted by SBAs, TBAs must be made 'safe' and know when to refer, with strong linkages to health facilities. Since they are the first point of contact for newborns, they should be familiar with basic resuscitation practices.

Joseph Ana (Nigeria): Are traditional birth attendants good for improving maternal and perinatal health? Yes. BMJ 2011; 342 https://doi.org/10.1136/bmj.d3310

Christabel Enweronu-Laryea (Ghana): Resuscitation at birth is not enough for quality health outcome. Quality supportive care in the hours after resuscitation is important to protect the brain from further damage. Such post-resuscitation care is not provided by TBAs and PHC facilities in many sub-Saharan African countries. Also, extra uterine transportation has its challenges because ambulance services (where they exist) are not equipped for newborn transport. These babies arrive to hospitals many hours after resuscitation in very poor condition. Many survive but with significant disability. Let us make every effort to ensure that receiving HBB in the community will not be the major cause of neuro developmental disability in low-resource countries in coming years.

Mike English (Kenya): We are working on trying to understand what gaps exist in the coverage and quality of care in Nairobi City County, Kenya, where neonatal mortality is estimated to be the highest of any county at 39/1000 livebirths, and 80% of births are estimated to be in health facilities. http://bmjopen.bmj.com/content/6/12/e012448
If anyone wants to examine the tools being used and use them for themselves then they have all been made available here: https://globalresearchmethods.tghn.org/methodology-projects/estimating-gaps-provision-and-quality-inpatient-newborn-care/

Oxygen, Respiratory Support, and Retinopathy of Prematurity

Ruth Davidge (South Africa): In South Africa we are focusing on developing care at lower levels as transport is a problem with often lengthy delays and there is inadequate capacity in central hospitals. We are developing capacity for delivering nCPAP at rural hospitals, supported by monthly visits from a consultant paediatrician and bimonthly visits from the specialist team.

Lily Kak: Because oxygen is so fundamental to high-quality inpatient newborn care, it is natural that increased availability of oxygen is one of the first steps taken into special newborn care. However, in most settings, the delivery systems provide high concentrations of oxygen, which can be toxic - especially to preterm infants. The ability to mix oxygen with air and deliver the exact amount of oxygen needed to keep blood levels of oxygen in a safe range requires routine pulse oximetry and the use of blenders for careful titration of supplemental oxygen concentrations. Staff need an understanding of the potential harm that high levels of oxygen can do to developing eyes and lungs, and staffing ratios must allow providers to monitor their patients frequently. New oxygen advocacy resources from PATH provides the data, messages, and resources to help understand the planning, policies, and technologies involved in oxygen delivery scale-up http://sites.path.org/oxygen-therapy-resources/oxygen-primer/

Clare Gilbert (UK): ROP is a major cause of blindness in children in many middle income countries and is becoming an increasingly important cause in low and low-middle income countries as neonatal services expand and more preterm babies survive. Recent estimates suggest that in the year 2010, 20,000 preterm infants become blind from ROP, and a further 12,300 visually impaired.. Currently only around half of these infants are treated due to lack of services, however screening and treatment of the sight-threatening stages of ROP is highly cost effective.
http://www.hifa.org/sites/default/files/pages/ROP%20for%20chifa%20Nov%209%202017%20C%20Gilbert1.pdf

Jaundice

Kojo Ahor-Essel (Ghana): I will want to make mention of the seemingly lack of training/knowledge about neonatal jaundice among health workers as well as the communities. Many babies are dying or developing permanent disabilities which are preventable.

I Abdulkadir (Nigeria): 3 years ago a group of researchers worked under the name ‘Stopping Kernicterus’ in Nigeria with collaborators in the US. Their yet unpublished work, which won the

global health innovative award 2016, showed how maternal education and early access to care remarkably reduced incidence of Kernicterus. They developed several tools for education of mothers and different categories of health workers.

Prematurity

Sarah Moxon (UK): It is well-know that preterm infants are at higher risk of childhood morbidities (including adverse visual, hearing and neuro-developmental outcomes). The lower the gestational age at birth, the higher the risk of difficulties. Most premature infants, especially those <34 weeks, will require facility based care for survival, including thermoregulation, respiratory support (oxygen, continuous positive airway pressure), treatment of specific complications (feeding, seizures, jaundice) and prevention and treatment of infections. Many of these interventions carry a risk of harm when not performed with safe equipment or by trained staff. This is increasingly apparent in middle-income settings, where we have seen an increase in impairments in survivors of neonatal care, especially where complex care has been scaled up without due attention to the quality of care, as quantified in the Beyond Newborn Survival series in 2013 https://www.nature.com/articles/pr2013202. Follow up programmes, early intervention (which is standard practice in higher income settings) and support services for parents of preterm survivors are urgently needed.

This new paper in The Lancet Global Health indicates a high prevalence of cerebral palsy in Uganda. The authors note (paradoxically) that improvements in newborn care in LMICs, especially for preterm infants, 'will probably increase the number of preterm children with cerebral palsy; this pattern occurred in North India during 2009'. http://dx.doi.org/10.1016/S2214-109X(17)30374-1

Melissa Gladstone (UK/Malawi): Our paper from Malawi demonstrates the high prematurity rate in a community based setting and the poor outcomes in both development and growth of those mainly born late-preterm http://journals.plos.org/plosmedicine/article?id=10.1371/journal.pmed.1001121

Neonatal encephalopathy

Matthew Ellis (UK): Given 50 million home births, almost all without skilled care and the limitations around recognition and prompt intervention for fetal compromise, even when it occurs in a LMIC health facility, the major contributing factor is intrapartum hypoxic injury.
Our modeled NE incidence suggests 1.15 million babies were affected in 2010, down from 1.60 million in 1990 (0.9% annual reduction). Of these babies with NE, 865,000 survived of which 233,000 (UR 163342,000) had moderate-severe impairment and 181,000 (UR 82319,000) had mild cognitive or motor impairment DOI:10.1038/pr.2013.206

Dave Woods (South Africa): While it is well known that the decreased uterine blood flow during prolonged or frequent contractions is usually the cause of the fetal hypoxia, maternal management often consists of giving the mother supplemental oxygen rather than stopping the contractions. The latter provides an opportunity to arrange transport or plan further intervention. To address fetal monitoring in a primary care setting and apply fetal resuscitation (turn the mother on her side and stop contractions with oral nifedipine) we have written a small booklet (Fetal Heart Rate Handbook) that others may find useful: www.bettercare.co.za

Feeding

Lily Kak: In all special newborn care units, maternal breast milk is the preferred source of nutrition. But only in exceptional units are mothers directly involved in feeding their infants if they are unable to suckle. Although mothers are encouraged to supply milk for their hospitalized infants, there is little early support for lactation (use of IV fluids may be prolonged), maternal presence in the unit is highly variable, and seldom is there an individualized feeding plan and daily growth monitoring with adjustment of intake as needed. Access to donor breast milk is very limited, so providers are forced to develop their own solutions when mother's milk is insufficient or not available.

Hygiene and infection control

Lily Kak: In most newborn special care units there is an area for handwashing with soap and water - although not all hospitals and health centers caring for small and sick newborns have a source of running water. In many units, more attention is devoted to wearing shoe covers and cover gowns than to enforcing handwashing. Crowding, with multiple babies sharing cots and radiant warmers also promotes the spread of infection. Some facilities are making their own waterless hand cleaner and positioning it at each bedside in the newborn care unit. WHOs multimodal strategy to improve the patient safety climate can be a foundation for improving handwashing, and new guidelines are available for disinfection of resuscitation equipment.

Family-centred care

Lily Kak: Many NICUs and SNCUs do not have an open-door policy except when the mother is needed for breastfeeding her stable baby. But some countries - such as Canada and India - are changing the paradigm of neonatal intensive care and integrating parents into the care team largely due to the evidence and advocacy of physicians from these countries. Does every country need a champion to advocate for such family-centered care? Does every country need to generate evidence on the approach?

Mike English: What we need for such a paradigm shift is long term engagement with national institutions (spanning government, education, health care training centres, and professional associations) to build and sustain locally owned initiatives.

Sarah Moxon: Family centred care is part of a more humanised, respectful approach to neonatal care with ample evidence that it has positive benefits for all involved. Champions are critical, but an entire health systems approach is required to change the culture of care-giving. In Northern European countries (eg. Sweden) neonatal units have been fully reconstructed to home families at the centre of the unit, and nurses and doctors to work around them. Highly complex procedures are performed with very small and sick babies in the skin-to-skin position. This extreme of family centered care no doubt relies on a health system that is well-equipped and resourced. However, this does not mean that family centred care has to be prohibitively costly, nor that resources are the only limiting factor. In fact, as with examples of successful kangaroo mother care programmes, evidence suggests that following initial 'start up' costs, there are long term cost saving benefits to the family centred approach.
In most settings there are forms of resistance to family-centered care. It was not long ago in the UK that mothers on the neonatal unit were perceived as jeopardising ward cleanliness and as a potential nuisance to the order and functioning of the ward. In some of my work with colleagues in Asian countries, we have discussed newer fears of litigation cases from parents coming into neonatal wards and suing for perceived malpractice.

Ruth Davidge: In my province we have a policy guiding hospitals on the provision of lodger facilities for mothers (and where possible fathers) of babies and children in hospital. Hospitals are required to provide accommodation and meals at least for all breast feeding mothers and up to half of their number of paediatric beds. Fathers are permitted 24hr access to their children (although some hospitals still only allow them during visiting hours!) and sibling visiting is encouraged. In the neonatal units mothers are encouraged to practice skin to skin care as often as possible until baby is ready for 24 hr KMC, and assist with all feeds, bathing of baby, cleaning the incubator daily and administering oral medication. We are also considering their role particularly in KMC of observing and recording observations for their baby.

Alison Taylor (UK): The focus and associated language within family centred care needs to change from that of permission, involvement and inclusion to that of negotiation, partnership and empowerment of children (where appropriate) and their families. This definitely extends to siblings who (despite this being much studied) are still sometimes marginalised. That said, critics of the family centred care model have pointed out that despite the best of intentions, the rights and interests of the

child can sometimes be overlooked in favour of those of the family. It can be very difficult to get the balance right.

Sarah Zadik (UK): Mothers of pre-term babies are at increased risk of post-natal depression. Involving these mothers, and fathers, in the care of the premature baby, giving them encouragement and family support may alleviate the postnatal depression, which helps the baby to thrive. This does not need any expensive equipment and in the long run is just as important as the technical care in the neonatal unit.

Follow-up care

Sarah Moxon: In Rwanda, Partners in Health-Inshuti Mu Buzima supported facilities provide follow up and support for survivors of preterm birth. What struck me was the potential scalability of the approach; it was nurse and social worker led, with developmental checks for the infants and young children following well-designed pictorial checklists. Simplified tools and monitoring systems had been developed for following up of the preterm babies after discharge from the special newborn care unit.

Sue Prullage (Rwanda): The Rwandan Neonatal Guidelines recommend a 2 week post discharge follow-up for weight and then they are to be followed at the health centers. We have it at the hospital where I work in Rwanda, but have difficulty in getting the families to return. The only time they will come is when they realize their baby is not developing as they should and then we have no real services to help them. We refer to physical therapy if they can't sit or walk. But the children that do not meet the social and language developmental milestones we have nothing to offer them. This just demonstrates that neonatal care is multi-faceted and all of this needs to be addressed as we talk about scaling up care for premature infants.

Christabel Enweronu-Laryea (Ghana): For low-resource settings prevention of severe disability is our best option as there are limited resources for children with disability. Inadequate location address system makes tracing parents who do not return for follow up difficult. Human resource limitations especially in district hospitals limits local post-discharge care and transportation costs to larger hospitals is a burden for families.

4. In what ways are health workers empowered/disempowered to provide adequate quality of care for newborns?

Skills/Training

Mike English: Most medical training schools I know in East Africa provide a total of 10 weeks paediatric training of which 2 weeks is neonatal care - and often the large numbers of students are not welcome on wards for infection control reasons!

Ruth Davidge: The failure to provide specifically allocated and trained nurses to care for sick and small babies is a huge problem and is not adequately addressed in the literature or global recommendations. The allocation of midwives to the care of sick and small newborns will always result in a conflict in priorities particularity in low resource settings as midwives have to choose whether to focus their time on the mother or the baby. Frequently hospitals allocate experienced and trained midwives to the labour ward and allocate junior, inexperienced and untrained nurses to the nursery. It is critical that globally there is increased advocacy that nurses are trained to care for sick and small babies specifically (neonatal nurses) and are permanently (non rotational) allocated to the care of these vulnerable babies.

Sue Prullage: We are launching a survey for neonatal nurses in 50 units across Rwanda, in order to identify the gaps in education, to help develop a workable education program, and develop neonatal nursing competencies for Rwanda.

Sarah Moxon: The nursing workforce is a critical issue for those of us supporting the global Every Newborn Action Plan. Led by UNICEF, we published a series of papers in 2015 on the health system bottlenecks to scaling up newborn care using data from 12 countries collected through national stakeholderworkshops https://bmcpregnancychildbirth.biomedcentral.com/articles/supplements/volume-15-supplement-2

Dave Woods: Where it is not affordable nor practical to send experienced mentors to assist with training in under resourced countries, much can still be achieved by enabling the local staff to manage their own continuing education provided appropriate learning material is made available. In South Africa we have successfully provided this material to over 100 000 midwives and doctors in the past 25 years: www.bettercare.co.za

Lily Kak: I don't think countries will be prepared to introduce a new cadre of neonatal nurses because of the widespread shortage of health providers in general, and of midwives and nurses in particular. WHO is conducting an online multi-country Midwifery Educator Survey among all those who teach midwifery skills, seeking to understand who cares for sick and small newborn babies and where they are cared for, how students are taught about caring for sick and small newborns, including what clinical skills are needed and what they should do to ensure a positive experience for the parents. USAID, UNICEF and multiple partners are supporting a separate multi-country situational analysis to determine facility readiness and quality of care for small and sick newborns and young infants. This activity will also provide useful information about neonatal nursing capacity and needs in 2018. No longer should issues of training, deployment, task-shifting, etc, among the carers of sick newborns be ad hoc.

Guidelines

Lily Kak: USAID and Every Preemie SCALE have produced a series of "Do No Harm" technical briefs covering four major areas of clinical service delivery for small and sick newborns; oxygen and respiratory care, thermal support, infection management/prevention, and feeding. Each of these gives examples of ways that unintended harm can result during special newborn care and provides updates on current recommendations and clinical guidelines. Each brief also includes potential action steps to improve care and health outcomes: http://www.everypreemie.org/donoharmbriefs/

Deborah van Dyke (USA): Global Health Media Project developed the Small Baby Series (in partnership with the American Academy of Pediatrics (AAP)), consisting of 27 short teaching videos. These cover many life-saving practices such as how to keep premature babies warm with skin-to-skin care, and how to feed them with a cup or feeding tube before they're strong enough to breastfeed. These can be narrated in your local language https://globalhealthmedia.org/videos/smallbaby/

NPW: We use The Safe Delivery App [http://www.maternity.dk/safe-delivery-app/] in Liberia, which provides skilled birth attendants direct and instant access to evidence-based and up-to-date clinical guidelines on basic emergency obstetric and neonatal care. The app leverages the growing ubiquity of mobile phones to provide life-saving information and guidance through easy-to-understand animated instruction videos, action cards and drug lists.

Ruth Davidge: In Kwa Zulu Natal, South Africa we have developed a standardised neonatal record keeping system and a facility based essential package of neonatal care and assessment tools. These are based in part on systems/tools developed/rolled out by the National DOH, to be used in all 52 hospitals providing maternity services.

Medicines

Samantha Sadoo: Many units experience a consistent lack of essential medications, or poor quality supplies. Parents are often requested to buy their baby's medication at the pharmacy to bring back to the ward. Improving information technology to manage logistics could improve needs-based forecast-

ing of supplies, although this is often non-existent in many settings, and doesn't solve the issue of inadequate funding. Other issues include a lack of a formulary or guidelines regarding the use and prescription of such medications, as well as an inadequate supply of accessory equipment such as cannulas and syringes to administer them.

Health information systems

Mike English: In many low-income countries sick newborns do not have their own medical record or patient number; if they are sick from the time of birth they are admitted under the mother's patient number. Also some systems are not able to capture data from newborn units as they have not traditionally been recognised as specific inpatient units. This typically means there are no data on admissions to or deaths in NBUs. As people become more interested in newborn care they are suddenly trying to add lots of quality of care indicators to proposed neonatal registers dramatically increasing the data collection workload usually for nurses who are already overstretched. Yet there is typically no investment in the system and people that will be required to analyse and use such data.