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Innovations: Supporting family integrated care

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ABSTRACT

Family integrated care is delivered in a supportive environment where parents are supported with education and competency based training and the neonatal unit policies and guidelines are conducive to providing such care and nurturing such approach. Use of digital technology has revolutionised and shaped the modern world. Use of mobile-based application can help parents to develop their knowledge and confidence; cameras and videos can help parents to stay in touch with the vulnerable infants even when they are not next to their loved ones. In this article we glance through the innovative ways of breaking through the barrier of staff and parent education, communication and access of the parents to the cotside using innovative ideas and digital technologies.

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1. Introduction

Family integrated care (FIC) is built on the basic principles of mutual respect and dignity, competency based training, education and active involvement of the parents in delivering care for their vulnerable infant admitted to the neonatal unit (Jiang et al., 2014; O'Brien et al., 2013). However, the environment, infrastructure, layouts and governance around neonatal care may not make it conducive for developing and nurturing such an approach. We are aware that in certain well-developed countries new neonatal units are built with the idea in mind of having the families living on the unit together with their babies; but such facilities and options may not yet be realistic in many neonatal units including the UK.

Therefore, active involvement of the families and a collaborative environment between the healthcare professionals and the parents often fall short, even with the best of intentions (Redshaw et al., 2010). Innovative ideas and use of technology can help to overcome some of these shortfalls. Parent education, access of the parents to the cotside and communication with the parents can minimise stress and anxiety, help them to gain control back and improve their coping skills. Healthcare professionals may find it difficult to embrace this paradigm shift in the FIC model from a doer to a facilitator and consultant for the parents (Kjellsdotter et al., 2017). Healthcare professionals, especially nurses are also constantly stretched in the face of severe shortage of skilled staff in neonatal units. Even providing education and updates for the

nurses in groups is very challenging. In such a situation, innovative ideas to train nurses are important to make them well conversant with this new model of care.

The FIC model developed by the Mount Sinai Hospital team is based on a large amount of experience co-designed material which is accessible in <http://familyintegratedcare.com/>, the majority of these materials are paper based. In this article, we will explore some of the new approaches which are taking family integrated care to the next level, by educating parents about neonatal care and practices, by training staff in innovative ways and by creating a friendly and welcoming neonatal environment for the parents.

1.1. Integrated family delivered care mobile app

Imperial neonatal service in collaboration with veteran parents and the core working group on family integrated care have developed Integrated Family Delivered Care (IFDC) mobile app to support parents in this new care model (Banerjee et al., 2017). In the modern world with easy access to internet parents often resort to online information from various search engines and forums where discussions around certain topics of medicine are generally regarded as more pessimistic and on majority of occasions unreliable; this can result in significant distress and anxiety (Usui et al., 2011). Both the POPPY project and Picker National Surveys highlighted the problem of inconsistent information received by parents from different members of the neonatal team (Redshaw et al., 2010). Providing clear consistent information is the key to parental education and understanding. The IFDC mobile app is freely available for both mobiles and tablets from both Apple Appstore for iOS

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devices and Google Playstore for Android devices for any parents around the world who are in need of information around neonatal care of their sick preterm infant. The App was funded by the Imperial Health Charity.

This app was experience co-designed with veteran parent focus group, medical, nursing and allied health professionals. There were several parent focus group discussions around the app design and content, which were attended by numerous parents and many healthcare professionals to finalise the end product. The app design was created by Pocket Explorers Limited (Hannah Catmur) and the app was developed by Propellers app developing company (Mike Adams). The Quality Improvement and Information Governance team from Imperial College Healthcare NHS Trust (ICHNT) were actively involved to make this app compliant with trust information governance, making sure the quality of the app was not diminished.

Parents can download the app and register with the required information with their username and password at the very beginning of their journey soon after admission. The personal details and diary entries in the app are only accessible to parents as it is password protected; the app can sync between various iOS devices making it easy to access from home, hospital or workplace. The IFDC mobile app can handle multiples upto quadruplets, which mean that parents with multiples, as is the case for many preterm births, create one entry with their username and password and will be able to add all their infants as multiples within the same entry separately. This is not the case for many other neonatal mobile apps. The IFDC mobile app has got an interactive and a non-interactive section. The non-interactive section is divided into several sections. The main focus of the non-interactive section is to deliver parental education and consists of fifteen chapters around

various aspects of neonatal care from admission to discharge written by our multidisciplinary team in collaboration with our veteran parent focus group (Fig. 1). To our knowledge, this is the only online parent friendly consistent resource in the world available to parents of sick preterm infants to such as high level. The chapters are comprehensive, written by trained professionals and co-designed with veteran parents. The chapters contain details around general aspect of the neonatal unit and the team, monitoring appliances, ventilators, medical conditions such as chronic lung disease and oxygen dependency, as well as developmental care, lactation and breast-feeding in premature infants. There are details around oral medications and preparation for discharge home. There is a glossary of common terms in the non-interactive section which is co-designed by the parents, explaining some of the medical jargon and abbreviations commonly used by the healthcare professionals in discussion with the parents (Fig. 2). The app also links to other reliable and trusted resources available on the internet. For example the Best Beginnings Small Wonders films that we used to give as a DVD copy but found many parents did not access it. In this way they can watch films easily via the links in the app.

Another important feature of the non-interactive section is the developmental timeline that we created, which is again a very unique feature. The developmental timeline is an educational tool around the development of the premature infant around various gestational ages from 23 to 42 weeks. This tool informs the parents about their general development, brain and sensory development, motor development and behaviour and about the neonatal care they generally receive around those gestations on a weekly basis, tailored to neonatal care (Fig. 3). It also informs parents about what they can do at those gestational ages regarding touch, bonding,

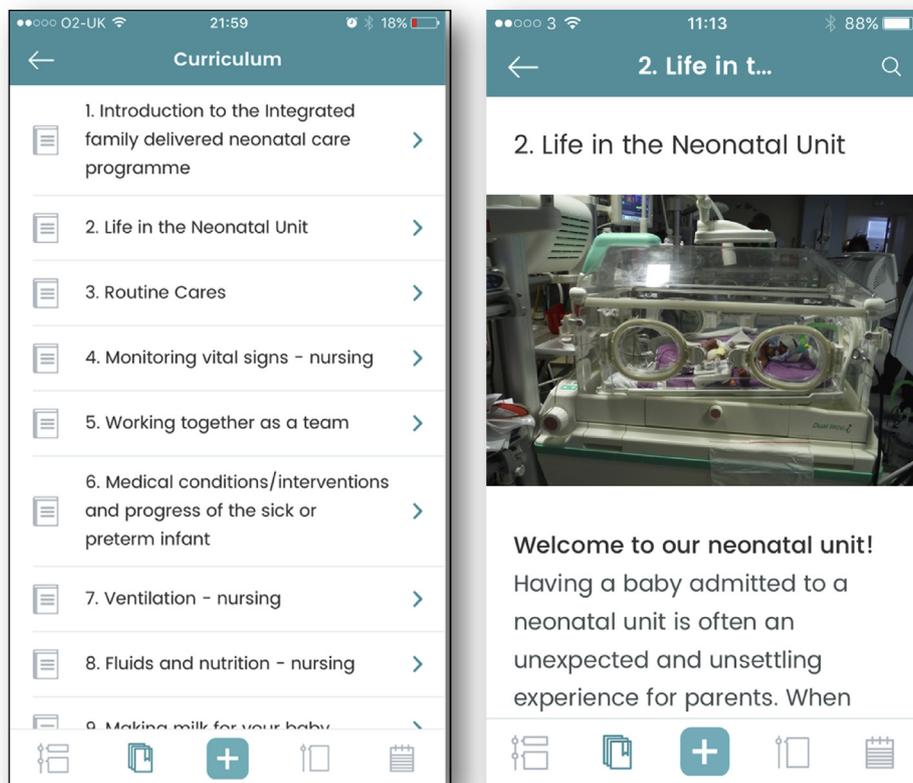


Fig. 1. Parent education training curriculum in the IFDC mobile application.

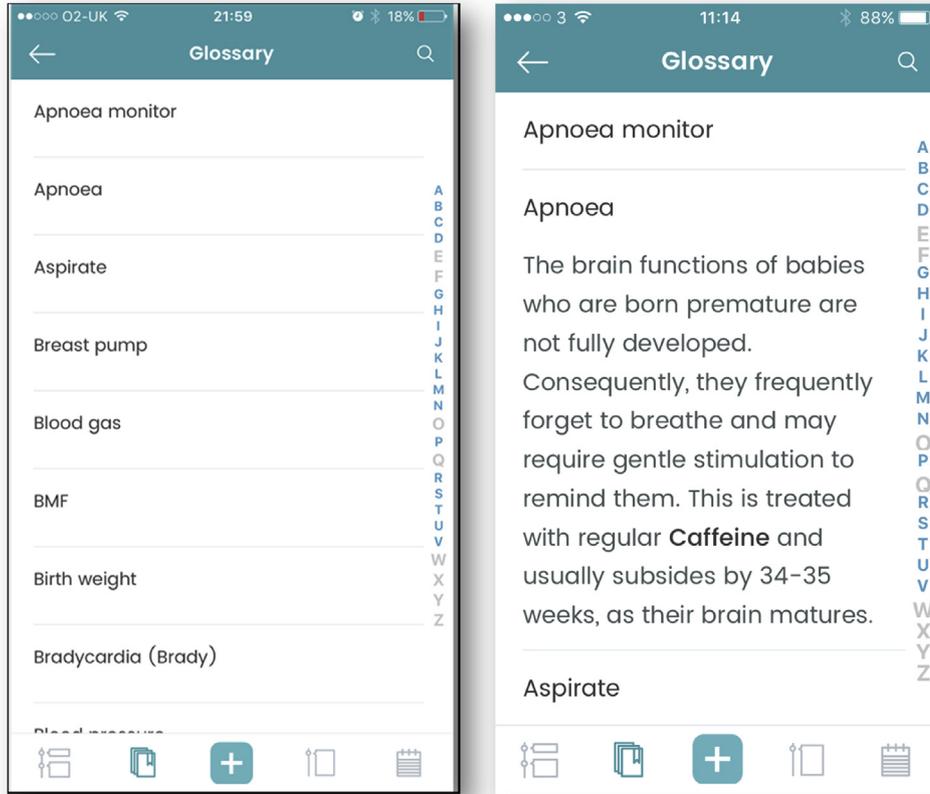


Fig. 2. Glossary of common jargons used in neonatology presented in the mobile app.

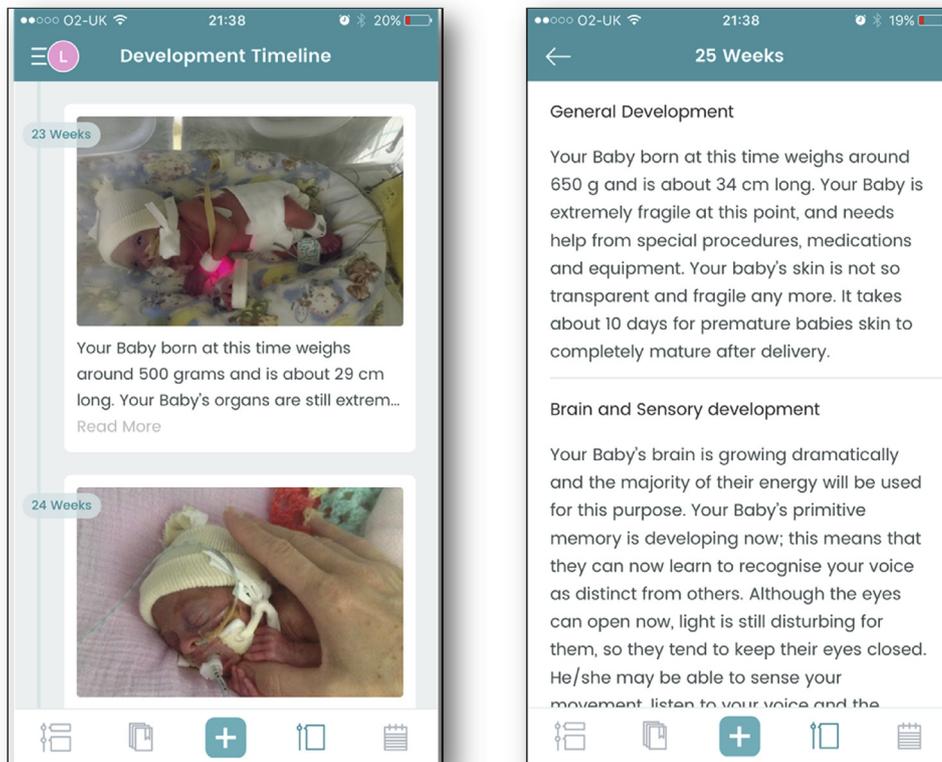


Fig. 3. Developmental timeline describing the developmental attributes of different gestational ages.

skin-to-skin, lactation and breast milk expression as well as general care such as nappy changes and oral or mouth care.

The interactive section of the app is a pioneering achievement of the Imperial IFDC team. It features a diary section (Fig. 4) where parents can record their entire journey in the NICU. They can record memories as text and upload pictures and videos from their smart phones or tablets. This record can then be seen by the other parent wherever they are if they have access to the app account. Alternatively, a parent can email the memory over the internet by tapping on the video or photo to extended members of family or friends if they wish helping the communication within their close social circle. This feature was added to the app following the idea by one of the parents from the veteran parent focus group.

Parents are also able to upload and chart their skin-to-skin cuddles, milk expression, feeding episodes in addition to their memories in the app. This gives them a visual impression of their breast milk expression volumes making their discussion with the lactation consultant and other members of the caregiving team easier. They are also able to chart their growth in terms of weight, length and head circumference in a contemporaneous manner thereby relating to their physical growth. Another section also allows the parents to write notes for themselves. This can be a reminder of what to discuss with the healthcare professionals during ward round or at a later date, or actually taking notes from a discussion with a consultant or other healthcare professionals. These records appear on their timeline that charts progress sequentially. This can be printed later and kept as a diary record for future memories.

The app focusses on education and concurrently allows parents to use it as a diary of their journey at the neonatal unit, and used not only by parents participating in the IFDC care model but universally on our units. We introduce the app to the parents soon after

admission, so they can benefit from it from the very beginning if they wish. Many parents who have used the app have found it an extremely useful educational resource and a way to save their memories; for some this could be a long and memorable period of their life. Most importantly, it enables the healthcare professionals to give consistent information to the parents without investing considerable amount of time for detailed discussions and for the parents getting reliable consistent information without searching individually for certain aspects of prematurity.

1.2. Access to admitted infants

Neonatal units across the world are extremely careful in safeguarding the sick infants admitted to the hospital. This requires rigorous governance and strict entry and visiting policies. Majority of the units in the UK have 24/7 access policy for the parents of the admitted infants (Redshaw et al., 2010). Some places will have separate policies for relatives and siblings to visit their newborn infants. In almost everywhere across the UK, the neonatal units have a locked door going to the clinical area to safeguard admitted infants. This can sometimes result in difficulties for the parents in accessing their infants. In situations when all the healthcare professionals are busy in a state of heightened activity of the neonatal unit, at night or weekends when fewer staffs are around the parents may have to wait for considerable period of time before gaining entry to the unit to see their babies. This may cause anxiety and distress to them, as they fear their entry is delayed because of an issue around their baby and is clearly a barrier of FIC. Many neonatal units have a policy of not allowing the parents to be at cotside during handovers and ward rounds, at best, some units will allow the parents to be there at the ward round when discussing their infants and are asked to leave when other infants are being discussed.

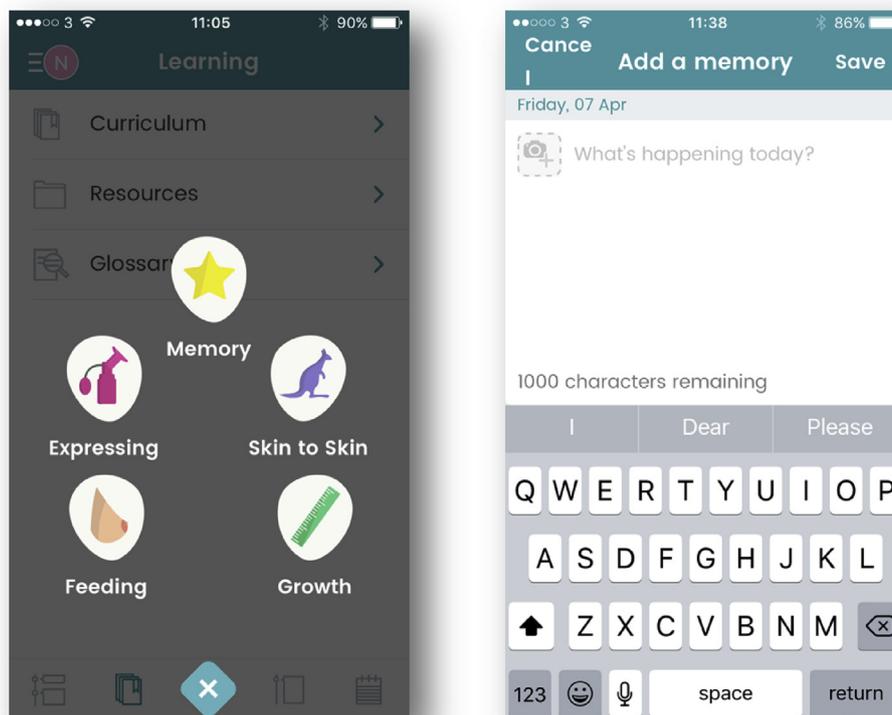


Fig. 4. The interactive section of the app has a diary element for parents to upload memories with pictures to the app.

1.3. Fingerprint entry

Some neonatal units in Canada have advocated for continuous seamless access for the parents to the neonatal units and have introduced techniques such as fingerprint access points (Fig. 5) and identity card access points to enter the neonatal unit. One of the neonatal units at Sunnybrook Health Science Centre in Toronto has introduced separate entry corridors for parents and healthcare professionals in their newly built neonatal unit. Some units in the UK have embraced the use of fingerprint scanners at the entry to the neonatal unit. These techniques are relatively cheap options, but need clinical governance policies and operating guidelines. One of the main arguments against parental free access to the neonatal unit is that this will allow anyone who may be following the legitimate parents to the neonatal unit, who do not have an access. Strict vigilance and parental education are required when installing a tool like this in the neonatal unit. In the majority of the units who have embraced fingerprint entry to the neonatal unit for the parents there is generally a registration policy for the parents, which is supported by the ward administrators and the access is revoked when the infant is discharged or in extenuating circumstances.

1.4. Headphones

As mentioned earlier, practice around parental presence during bedside medical ward rounds and handovers is variable amongst UK neonatal units (Redshaw et al., 2010; Abdel-Latif et al., 2015; Cameron et al., 2009). The relationship between parental attachment and better neurodevelopmental outcomes is well known in preterm infants (Reynolds et al., 2013). According to a UK based survey of preterm neonatal infants parents were routinely present on the ward round in 86% of the units (Redshaw et al., 2010) and recent studies have shown strong support from healthcare professionals for parental presence at the ward rounds (Abdel-Latif et al., 2015). We should recognize the psychological state of the parents of a critically ill baby who can feel helpless at the cot-side. Parental access to their infants can be severely compromised when their babies are undergoing intensive care resulting in anxiety and create a barrier to the natural bonding process. Additionally, to ensure confidentiality during ward rounds and handovers, in the majority of the neonatal units across UK, parents are asked to leave the cot-side once their baby has been assessed. On occasions depending on the acuity of the neonatal units, the ward round can take a variable amount of time from 1 h to several hours, thereby increasing separation time. This can further build the anxiety, stress and frustration of the parents.

At the Imperial neonatal units we introduced sound blocking headphones as a quality improvement initiative for parents to remain at the cot-side during handovers and ward rounds (Deierl et al., 2015). The Venitex Pit-Radio Electronic Ear Defenders were completely soundproof and have an inbuilt wireless radio for parents to listen to music (Fig. 6). The aim of the initiative was enabling uninterrupted parental presence at cot-side resulting in transparency, better understanding and communication and equal collaboration between parents and healthcare professionals (Cameron et al., 2009). This initiative resulted in true 24/7 access to the cot-side, eliminated separation time related to medical, nursing handovers and ward rounds and received positive feedback from both parents and staff. The results of this quality improvement initiative are being published separately soon. We believe that using sound blocking headphones is an effective and innovative way to maintain confidentiality and reduce parental separation in neonatal units with large shared nurseries, and has now been used more widely in UK and abroad as “best practice” in units focusing on FIC and allowing parents to be presence at cot-side during medical ward rounds and handovers.

1.5. Communicating with parents: secure video messaging system

Some neonatal units across UK are utilising a secure video messaging system for families of the admitted infants called vCreate: www.vcreate.tv/nhs. This system allows healthcare professionals looking after the infant to send the parents a short video message of their infants (e.g. 10–20 s). These video messages are meant to be general updates of their infants and can have embedded messages on the video such as, ‘I am waiting for you mummy for my 9 o'clock cares and feed’, and do not contain sensitive or clinical information. These messages are created using a dedicated device, such as a tablet, kept in the Neonatal Unit and sent to parents securely using a web based platform called the vCreate system (Fig. 7). Video messages can only be accessed by parents using their own secure login. These video messages are deleted after 3 months, or earlier if parent's request. Parents can download all their videos before deletion as a keepsake memory. The benefits of the system are manifold; parents receive reassuring updates on their infant's wellbeing whilst not in the neonatal unit resulting in unit staff spending less time answering the phone and more time on clinical care of the infants. This system can be used to help bonding for mothers who are medically unstable to come up to the neonatal unit following their delivery as they can receive several short videos during the first 24 h. This may also encourage



Fig. 5. Fingerprint access points outside the neonatal unit for parent access.



Fig. 6. Use of headphones in the neonatal unit.

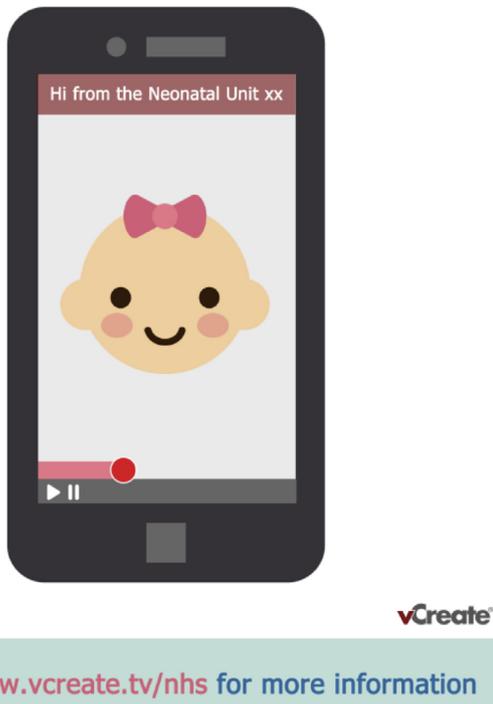


Fig. 7. vCreate secure messaging system.

parents to visit and be with their baby; using video messages can share important moments the parents may miss such as following extubation or weighing them at night time etc. This can be used as a mode to promote general news and updates such as parent education sessions when initiating FIC in the neonatal unit. The Royal Hospital for Children, Glasgow have successfully rolled out vCreate to their neonatal unit (<http://www.bbc.co.uk/news/uk-scotland-glasgow-west-39615463>) and had excellent feedback from parents and staff. Following this success vCreate team is enabling free access to their web-based platform to all 200 NHS neonatal units across UK at no cost, and our service is in the process of implementation. The initiative will be funded through corporate sponsorship for joint PR opportunities and branding of secure messaging application. The vCreate system has just won the prestigious Health Tech News “Winner of the Year” award (<http://www.thehtn.co.uk/2017/11/08/htn-awards-2017-winners/>).

1.6. New ways of staff training - bite size teaching

Ongoing training for nurses and doctors is paramount in providing good quality neonatal care. There is a constant shortage of trained healthcare professionals, especially nurses in the neonatal sector (Triggle, 2015) and <https://www.theguardian.com/society/2015/oct/19/bliss-neonatal-intensive-care-units-stretched>). This has resulted in acute shortage of nursing staff in the neonatal units across UK. Initiating FIC in the neonatal units require intensive training and support for the neonatal staff. However, whilst the service is stretched to its limits, management is reticent in releasing nursing staff for education and training in spite of best intentions, just to keep neonatal service afloat. In such a situation, innovative ways of training the nursing staff is required to initiate FIC in the neonatal units.

Imperial neonatal units have developed ‘Bite size teaching’ (BST) pack for training the nursing and other healthcare staff in the neonatal unit by bringing teaching to cotside avoiding long periods

of study leave and time away from the clinical area. Further details of the development of this pack are described in the staff education paper in this edition of the journal. The philosophy of BST is taking the teaching to cotside for the nurses who are finding difficult to attend group lectures and teaching programmes. The allied healthcare professionals along with nurses and breast-feeding consultants have created BST module for various topics from breast-feeding techniques, developmental care to communication with parents. Each module consists of a small box, which contains teaching materials and props. The BST team simultaneously runs a half-day ‘Train the Trainers’ course where the certified professionals will be able to become teachers in the BST modules. The idea is simple but innovative and can be used in many settings across the neonatal units in the world where access to training for the nurses are difficult.

2. Conclusion

There is growing evidence that FIC is the most efficient way of providing high quality care to the parent-baby-unit across neonatal services. But initiating FIC in neonatal units requires parental and staff training and a neonatal environment conducive in providing FIC. Current lack of resources within NHS and stretch in the capacity of the services requires innovative approaches to make this a reality. The Imperial IFDC mobile application can help to provide parental education and training as a basis of the competency based training programme for FIC. The parents gain confidence and knowledge empowering them to be an integral part of their infant's care giving team. Simple modification of the neonatal unit environment is one of the key elements to successful FIC in the neonatal units. Use of 24/7 seamless parental access to the cotside reduces anxiety and stress and increase parental satisfaction. This may require some adjustments such as providing parents with fingerprint entry or access cards; and use of headphones could be an innovative way to allow parents to be at the cotside without impairing patient confidentiality. Bite size teaching enables the staff to be trained at bedside without taking them out of their clinical duties. We strongly believe that even when the neonatal service is stretched to its limits, the use of innovative approaches to parent and staff education and perhaps making some minor modifications to allow parental access will help FIC flourish in the neonatal units across the UK.

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