



Foreword to the special edition on family integrated neonatal care

In this special edition we aim to provide guidance on how to implement Family Integrated Care (FIC) in neonatal units. This is a pathway the multidisciplinary team (MDT) developed several years ago, and we hope that sharing this material more widely can help many units achieve a change towards this new model of care in which we strongly believe.

The Neonatal Team at Imperial College Healthcare NHS Trust hold a shared vision and is strongly committed to provide excellent, family centred, caring and compassionate care for our premature and term babies and families. The Imperial Neonatal Service specialises in caring for extremely premature babies with 900 admissions and 300 babies born <30 weeks gestation in 2016. The Neonatal Units' ethos has always strongly supported parent involvement and delivered high quality family centred care. We have a well-established MDT consisting of dietitian, speech and language therapist, occupational therapist, physiotherapist, pharmacist, discharge co-ordinator and clinical psychologist with regular MDT ward rounds and parent support groups. We are home to the UK's oldest human milk bank and have nursery nurses qualified as lactation consultants. This support for mothers results in above national average breastfeeding rates at discharge. Parents can be with their babies 24 hours a day and we encourage them to be involved in their baby's care and attend ward rounds. We have parent rooms and kitchen facilities.

The team was inspired to be a pioneer in piloting Family Integrated Care in the UK as a Quality Improvement (QI) project, in order to further develop this model of care. On-going collaboration was established with the Mount Sinai Hospital team led by Prof Shoo Lee and Dr Karel O'Brien, who kindly have written the editorial for this special edition. Our service was the first in the UK to implement Family Integrated Care in a Neonatal Intensive Care Unit.

The overall aim of our project is to improve the parent experience and parent-infant bonding, parental mental health, infant health outcomes in line with international evidence around FIC models and the British Association of Perinatal Medicine (BAPM) clinical strategy.

A PDSA cycle (Langley 1996) was created to demonstrate the model for improvement. This quality improvement programme was funded by Imperial Health Charity.

The IFDC team

The IFDC core group was established in 2014 and the project was fully implemented in April 2017 with the development of high quality experience co-designed supporting material including a parent supporting mobile App and parent competency based training programme. This material was shared with other neonatal units and national organisations such as Bliss and the London Neonatal Operational Delivery Network.

Fig. 1. PDSA cycle.



Dr Aniko Deierl, Project Lead

"I am a Consultant Neonatologist at Imperial College NHS Healthcare Trust since 2012. I completed my training in Paediatrics and Neonatology and was awarded a PhD in neuroprotection in Hungary, at Semmelweis University. I have worked at Imperial for many years and continued to show interest in neonatal neuroprotection studies working with Professor Denis Azzopardi. In the last years, I completed an MSc in healthcare leadership and changed my interest towards

quality improvement methods. I am leading on the IFDC Project for Imperial Neonatal Services, and this project was my dream for the last 3 years. We worked hard with our excellent multidisciplinary team to make it real just as we imagined”.



Dr Jayanta Banerjee, Project Co-Lead

“I am a Consultant Neonatologist at Imperial College NHS Healthcare Trust since 2014. I completed my graduation from Calcutta Medical College in India and did most of my neonatal training in the UK. My research interest includes neonatal haemodynamics and oxygenation, and was awarded with an MD in this field.

I am innovative and have been involved in service development projects within

NHS.

My aim is to pioneer family delivered care at the Imperial College hospitals and strongly believe this to be standard of care in the UK within the next few years”.



Annie Aloysius

“I have worked in neonatal care at Imperial College NHS Healthcare Trust for over 20 years as a Speech and Language Therapist and Lactation Consultant (IBCLC), working to support sick and preterm babies and their families with feeding and early communication. My associated work with UNICEF UK Baby Friendly Initiative, Bliss, Best Beginnings-Small Wonders and Birthlink UK charities

have consolidated my belief that it is only through partnership with parents that we can achieve the best neonatal outcomes. With my colleagues, I am leading on the IFDC Project from the Therapist's side. I worked on material on lactation, journey to suck feed and many other chapters for the App”.



Karen Platonos

“I qualified as neonatal nursery nurse in 1981 and gained qualification as a lactation consultant in 2010. I have worked in a level 3 neonatal unit at Imperial College Healthcare NHS Trust for more than 20 years, supporting breastfeeding and early expressing. I have great enthusiasm of supporting parents in transition to

home and breastfeeding, and working very closely with many of our families. I worked on material on lactation, journey to suck feed and routine care for the App”. Karen is now our IFDC coordinator at Queen Charlotte's and Chelsea Hospital.



Beverely Hicks

“I am an Occupational Therapist who have worked with preterm infants for the past 11 years. As an OT I help to adapt the environment and individualise care to support each infant's sensory, social and motor development. My specialist area of interest is supporting babies through stressful and painful procedures. I worked on material on developmental care for the App”.



Stephanie Clark and Caroline King

“We are Neonatal and Paediatric Dietitians at Imperial College NHS Healthcare Trust, specialising in the nutrition of pre-term babies. We monitor and advise on our babies' nutrition and growth

throughout their journey on the neonatal unit from birth through to discharge. We keep in contact with our families post-discharge in the community and provide advice and growth monitoring as required. We work closely with the wider neonatal team, particularly with the multidisciplinary therapists and the discharge coordinators. We have been involved in the IFDC Project, working on material for the nutrition and growth chapters for the App”.



Maryam Kharusi and Robyn Winter

“We as Discharge and Liaison team cover both Imperial Neonatal Units. We work in partnership with neonatal staff, allied health professionals, other hospitals and community agencies, as we support the discharge process and facilitate a smooth and timely discharge home for vulnerable, high-risk babies and their families providing continuing care in the community. We co-ordinate discharges for babies with more complex needs, such as home oxygen or nasogastric tube feeding. We worked on material on discharge planning for the App”.



**Rosie Hurlston
and
Becky
Armstrong**

“We as Clinical Psychology team cover both Imperial Neonatal Units. We work in partnership with parents, neonatal staff, and

allied health professionals. We have been involved in the IFDC Project, working on few chapters for the App”.



**Dr Sunit Godambe, Head of Specialty
2012–17**

“I am working as a Consultant Neonatologist at Imperial College Healthcare NHS Trust since 2005. I took over as the Head of Specialty for the Imperial Neonatal Services from 2012 to 2017. The IFDC Project is a Strategic project for Imperial Neonatal Service and will pave the way to a very humane model of care for our tiny babies looked after on both of the Imperial neonatal units. I hope we can roll it out as a standard care model for all our babies over the next few years”.



Sophie Williams

“I work as an Assistant Psychologist on the Imperial neonatal units, working alongside the multidisciplinary team to psychologically support families and babies in their journey, as well as contributing to the evaluation and implementation of the IFDC project. I have experience in supporting parent-child relationships and development across the lifespan in a variety of parent and child mental health services, and I am pleased to be a part of a project which empowers parents to be involved in their baby's care in these early, and often extremely challenging few weeks”.



Dr Lidia Tyszczyk, Head of Specialty 2017

“I have been a Consultant Neonatologist at Imperial College Healthcare NHS Trust since 2003. I am the Lead Clinician for the North West London Neonatal Network and currently the Head of Specialty for the Imperial Neonatal Service. The IFDC Project has already had an impact on the quality of care provided to babies and families. I am committed to supporting this model of care in the NWL Neonatal Network”.



Ines Silva

“I am a Neonatal Nurse that has worked in both medical and surgical neonatal units with over 10 year experience. Apart from patient care clinical skills, and staff education, I have special interest in quality improvement. I support the development of a working culture in which learning is encouraged, health care professionals work together and individuals are valued. Working in close partnership with the families was always part of my care philosophy, supporting them along their journey in the neonatal unit by promoting independence and helping them to build confidence”. Ines is now our IFDC coordinator at St Marys Hospital.



Martina Dinneen, Executive Sponsor

Martina Dinneen the Divisional Director of Operation for Women's and Children at Imperial College Healthcare NHS. Our team approached her during the initial planning phase of this project. As an executive sponsor she supported this project from securing funding to completion.

Other members of the Neonatal Team

There are many more names: nurses and senior nurses, allied health professionals, junior doctors, consultants, and the psychology team who also contributed to this project and provided on-going support.

Veteran parents

Our veteran parents provided an extremely valuable resource in the creation of this mobile application and project material. They sent photos and videos, written their journey, read and corrected the educational chapters and attended our focus group events. We are particularly grateful to: Christina You, Daniela Stablum, Adele Yemm, Sarah Fraser, Senna Quaye, Misty Gale and Angela Kay.



Marianna Loizia

“I am a PA in the Neonatal Service at Imperial College NHS Healthcare Trust, providing administrative support for the Neonatal Consultants and also the IFDC Project. I have worked at Imperial for many years and am very excited to be involved in a project that involves and empowers the parents in their baby's care from an early stage”.



Hannah Catmur

I'm a visual and UI designer with strong UX sensibilities. With 8 years of professional experience, I'm well versed in producing work that satisfies clients and keeps users happy. I studied at Leeds University and Carleton in Canada, achieving an International degree in Design and Communication.

I mostly work with crazy entrepreneurs, tech-startups and cool established companies. I love working on great projects from initial concepts through to final execution and IFDC Project has been an absolute pleasure.

Past clients include: Audi,

Center Parcs, Tesco, Goldman Sachs, News International.



Propeller

A small Cardiff development team, that specialise in cross platform digital development, creating applications for Mobile and Web.

Offering more than 10 years experience, we have a varied skill set that makes us an ideal partnership to undertake the IFDC App.

We are highly proficient on both sides of the development 'track, either it's bringing a design to life via code, or building complex backend for cross platforms applications.

Past clients include: YMCA, Cardiff University, TAXO'D, Spinning Head Productions, CS Properties.



Imperial Health Charity

Ian Lush Chief Executive, Imperial Health Charity

Imperial Health Charity supports the five hospitals of the Imperial College Healthcare NHS Trust. We give many grants each year, from a few hundred pounds to help a patient facing financial hardship to capital support in the millions. Few grants, however, have had the immediate and lasting impact of the £180,000 we gave to the Integrated Family Delivered Care

project run by our wonderful neonatal team at Queen Charlotte's and St Mary's Hospitals. Parents of a very premature baby face a hugely challenging and emotionally draining time, and this Project has tackled that challenge head on, providing remarkable levels of support, advice and involvement in the care of their babies for all parents – in part thanks to the fact that this was developed in partnership with parents.

In January 2017 my brother in law and sister in law had twin babies at 28 weeks, born in a hospital in Germany. The medical care was excellent and the baby girls are both now doing very well, but nonetheless there were many times during their eight weeks in hospital when the parents felt a real sense of isolation and bewilderment at their situation. Had they been able to access Integrated Family Delivered Care along with the app I am sure their situation would have been made just that bit easier to bear – and that small but significant reduction in stress for parents of these tiny, vulnerable babies is the reason why we are so proud to have supported this project.

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Karen Platonos, Lidia Tyszcuk
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