

An International Exploration of Improving Outcomes
for Extremely Preterm Babies
“Project EQUiP”



Churchill Fellowship - 2018

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Glossary

BAPM:	British Association of Perinatal Medicine
BPD:	Bronchopulmonary dysplasia, also known as CLD (Chronic lung disease)
CNN:	Canadian Neonatal Network
DCC:	Delayed (deferred) cord clamping
EPB:	Extremely Preterm Baby; born before 28 weeks gestation
EPIQ:	Evidence Based Practise for Improving Quality
FiCare:	Family Integrated (or family centred) Care
HCP:	Healthcare professionals
iNeo:	International neonatal research collaborative
NICU:	Neonatal Intensive Care Unit
NMCS:	Neonatal Mutual Co-operative System; Kansai (Japan) regional neonatal collaborative
ODN:	Operational Delivery Network; regional network for neonatal care organisation
PDSA:	Plan-Do-Study-Act, QI methodology
QI:	Quality Improvement
RT	Respiratory therapist
USS:	Ultrasound scan

Executive Summary

Exploring Quality Improvement Internationally for Preterms #EQUIP.

Outcomes are improving worldwide for extremely preterm babies (EPBs), but the risks of death or significant long-term impairments remain significant. Canada has addressed wide variation in neonatal outcomes with an innovative improvement programme: EPIQ. Draft guidance from BAPM is anticipated to propose that infants from 22 weeks gestation be considered for survival focussed intensive care in the UK. If we are to broaden access to intensive care, now is the time to learn from countries already practising at such boundaries; international analysis consistently quantifies the highest chance of survival at the gestations in Japan. Though UK programmes have been rolled out to support improvements in care, translating central initiatives into sustained changes in outcomes remains complex. My observations suggested that innovations in kit and technology are rarely the panacea; interaction of culture, people and systems are the real substance.

Key clinical areas of interest were those with greatest potential to translate improvements back to the UK:

- **Care in the first hours of life**
- **Neuroprotection and neuropromotion**
- **Infection control practices**
- **Gut health and breast milk**

Japanese utilisation of **digital infrastructure** was remarkable. There are no robust barriers preventing such transformation in UK units.

- Digital systems supported detail, clarity and accuracy in care, with the ability to review and learn from care episodes in near real time.

The **conformity of Japanese culture** was apparent during my observations, but the climate of teams was neither closed, static, nor with a fixed gradient of authority.

- Senior clinicians were supportive, encouraging and motivated to “grow” their junior colleagues, bringing about their development to exceed that of themselves.
- The theme of professional dedication and satisfaction was recurrent; summarised as “**Ikigai**”
- Whilst this can’t be transplanted or borrowed from one culture to another, the concept of committed passionate leadership inspiring future generations of practitioner, is highly tangible.

“...this is a calling, we have an absolute responsibility to these babies and families.”

Clinical management during the **designated “acute phase” of 72 hours** for EPBs in Japan represents a valuable target for our improvement efforts.

- Teams had a unified and articulated goal of avoiding IVH and brain injury, ensuring stability of physiology as far as possible.

- The gentle handling approach was both straightforward, achievable and clearly shared among the multi-professional team.
- The ethos to make the “right thing” the most straightforward one, was one I embrace wholeheartedly and would encourage.

The **CNN high-quality database**, free at the point of access, facilitates high quality research where supported by a clear proposal from professionals.

- This marries with the EPIQ programme, underpinned by applying high-quality evidence, using hospital specific data to generate improvement targets, and contributing to a national network for collaboration.
- National CNN “Evaluation Groups” work on specified themes e.g. brain health, developing a menu of evidence-based interventions and approaches.
- Whilst there is surface similarity to UK NICE guidance, where NICE guidelines are often implemented “as is” as best practice, the Canadian model supports selecting interventions “pic’n’mix”.
- A highly valued aspect of EPIQ was site-swap visits; practitioners targeting the same quality outcome visit one another’s institutions.
- The greatest impediment to effective QI was a lack of consistency among senior clinicians.
- QI project implementation and oversight should encompass compassionate, emotionally intelligent leadership, and be committed to valuing the team. These improvement interventions likely to be accepted, embraced and to effect change.

Parent isolation and **lack of perceived support** from peer parents was a clear and well vocalised focus for improvement efforts.

- QI efforts concerning peer volunteers on NICU had been extremely well received.
- The parents who had directly engaged with these projects valued their role tremendously and found satisfaction and pride in giving their time to others in a painful and challenging situation.
- Outstanding areas for urgent QI were inter-hospital transport and retrieval, and consistency of care provision between regional hospitals.
- Development of supportive, nurturing and empowering relationships during the NICU journey, could be built upon with involvement in service developments culminating in true co-leadership of QI with parents as partners.

This study of policies, practices and people does not suggest that we blindly emulate Japanese practice in the hope that we happen upon a “magic recipe” for intact survival among babies born at threshold viability. I would instead support a **critical, well-measured and locally tailored review of options for service improvement**. Translating rather than transplanting management approaches is likely to deliver the marginal gains which could progressively increment our key outcome measures.

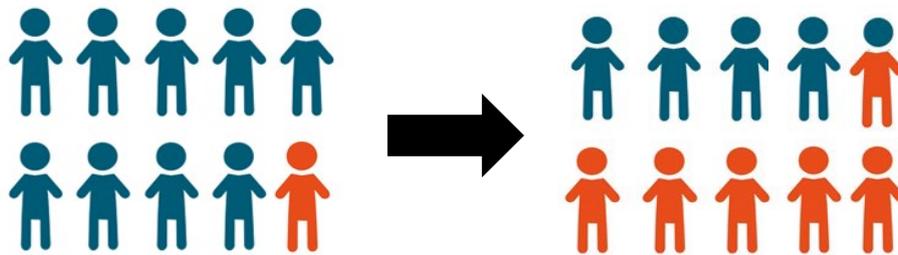
Summary Recommendations

- A focus on optimising early care for EPBs should generate a menu of interventions and approaches which can be shared through a comprehensive national database for exploring QI among preterms.
- To build upon active improvement initiatives in the UK, such as the maternal and neonatal health safety collaborative, the neonatal community should develop and sustain specific intra and inter-national relationships tailored to support high quality QI in all neonatal services. This could include a formal, long-term QI collaboration among all NICUs in the UK, akin to EPIQ Canada.
- Neonatal services should urgently lobby for accelerated digital transformation to support effective care of the EPB. This should be a key NHS priority aligning with the Long Term Plan and Neonatal Critical Care Transformation Review, supporting release of staff time to realise improvement work, simultaneously enhancing real-time data capture for QI.
- Neonatal services should review innovative solutions to establish, or embed, dedicated roles for neonatal QI, considering the added value likely to be achieved for the service. These roles should not be profession specific and should be supported by targeted training in Improvement and Human Factors sciences.
- Effective responses to national benchmarking, such as the NNAP and MBRRACE reports, would be supported by an open access neonatal community database of all improvement projects undertaken within NICU services. NICUs should support and encourage sharing of both effective and unsuccessful projects within and between their respective ODNs.
- NICUs and ODNs should devise annual strategies for improvement including no more than 3 simultaneous foci for change to reduce the impact of “change fatigue” on teams. These should be monitored and reviewed by the multi-professional team and led by a nominated Quality Lead for each service.

November 2019

1.0 Background & Context: The Why

Extremely preterm birth has extensive implications for those babies, their families, healthcare services and wider society.



Whilst only 10% of births occur before 32 weeks gestation, they regrettably represent over half of neonatal deaths

Outcomes are improving worldwide for these extremely preterm babies (EPBs), but the risks of death or significant long-term impairments remain significant. Recent data from neonatal intensive care units (NICU) in England certainly demonstrate improved survival, predominantly for those born before 26 weeks of pregnancy (Santhakumaran *et al.*, 2018). Figures available at the time of developing this project described around 1 in 3 of the most immature babies surviving to their 1st birthday. Of survivors from this group, one third would be expected to have significant developmental impairments affecting both them and their family. Many more than this can expect difficulties with their cognitive, sensory, physical or motor development. Though these might not be categorised as “severe” they may still represent a daily challenge or burden for these children, their families, and health and social care services.

1.1 Intra and Inter-national variation

Reports continue to acknowledge the challenging variation in key morbidities and mortality for EPBs. A comparison among EPBs from 19 regions of 11 countries revealed rates from 16% - 40% for one or more major neonatal morbidities among survivors born before 28 weeks (Edstedt Bonamy *et al.*, 2019). Across the UK rates of survival and/or impairment vary up to 3-fold between NICUs. Canada has acknowledged and addressed such variation within their neonatal network (CNN) with a novel improvement programme – EPIQ: Evidence Based Practise for Improving Quality.

1.2 Survival; not a simple story

Contemporaneous to UK figures around 1 in 3 survivors below 25 weeks gestation, Japan described close to 3 in 4 babies surviving; with no detectably higher significant impairments. A detailed comparison of 10 international datasets by the iNeo collaborative further quantified leaders in survival among more than 90,000 infants born very preterm (Helenius *et al.*, 2017). Between 2007 and 2013 the highest chance of survival was seen in Japan, with the greatest difference observed around 24 weeks gestation - Japan reached a remarkable 84% survival at the time. This has been speculated to

be specific to genetics, cultural practices not feasible elsewhere, more advanced equipment, or potential discrepancies in data definitions.

Japan was heralded as a role model for both maternal and neonatal care in 2014 with respect to their outstanding reduction in neonatal mortality; from 2.5 to 1 death per 1000 live births between 1990 and 2013 (Unicef; 2019). The same epoch saw UK improvements from a sobering 4.8, to 2.8 deaths per 1000, with few economically developed countries aside from the USA showing less improvement.

The possibility of sharing and learning from Japan’s incredible achievements represents an exceptional opportunity for the rest of the world.

I.3 “Doing Improvement” in Neonatal Care

Current UK recommendations are for prompt, collaborative approaches to reducing neonatal deaths. Though national policies and programmes exist to support improvements in maternal and neonatal care, translating to tangible changes to be embedded by healthcare professionals is complex. The literature clearly describes policies and guidance on “how to improve” rarely lead to sustained changes in isolation.

Draft guidance from BAPM (British Association of Perinatal Medicine), under review at the time of writing this report, is anticipated to propose that infants from 22 weeks gestation be considered for potential stabilisation, resuscitation and survival focussed intensive care. Routine practice would currently be for this to commence only from 23 weeks in the UK; Japan’s threshold of viability has been 22 weeks since 1991. If we are to extend these boundaries at which we offer such intensive care, now is the time to learn and benefit from experience of countries already practising in this way.

My fellowship project proposed to blend Japan’s clinical excellence in outcomes for EPBs with Canada’s ability to innovate and collaborate for improvement

My fellowship thus sought to identify “all the small things”; those seemingly minor, day-to-day practices, actions and processes which when put together equal more than the sum of their parts for neonatal care. An obvious parallel is the principle of “marginal gains” from the sporting world – identifying and adapting all those factors which may each contribute just a fraction to the positive outcomes, but which in combination deliver excellence. Neonatal risk reduction is a highly cost-effective healthcare intervention with huge potential gains for both the constrained NHS and its’ services, as well as infants and their families.

2.0 The How

2.1 Project Aims

To appreciate and understand identifiable factors contributing to Japan's excellent, aspirational neonatal outcomes for EPBs by visiting NICUs in Japan.

To gain an awareness of components of the Canadian Neonatal Network's (CNN) ability to transform neonatal care and outcomes achieved.

To take both these aspects and identify relevance directly to QI for neonatal practice in the UK.

2.2 Project Objectives

To identify specific, tangible Japanese policies, practices and personal professional elements which form the content of EPB care, and evaluate their real-life applications, benefits & challenges, by direct observation, exploration and discussion with a range of healthcare professionals (HCPs).

To be able to critically evaluate the Canadian QI approach to neonatology "EPIQ", to describe and propose relevant approaches which may contribute directly to 1) Reducing outcome variation for EPBs in the UK, and 2) Improve future intact survival for EPBs.

To propose and support development of specific, practical and scalable pilots for improvements in EPB care utilising the unique combination of experience from Japan and Canada.

2.3 Project Approach

My fellowship spanned December 2018 to February 2019. The content of this report comes from direct observations and interviews with clinical teams and families with their full consent. My shadowing, observations and general discussions were supplemented with focus groups of clinical and/or research teams and trainees, one on one meetings with individual practitioners and parents of extremely preterm babies and review of local and national guidelines, databases and policies.

My first visit was to the Center for Maternal-Fetal, Neonatal and Reproductive Medicine in Tokyo, hosted at the National Centre for Child Health and Development, Japan. Professors Isayama and Itoh in Tokyo also represented the Neonatal Research Network of Japan, and the iNeo international neonatal research collaborative for the purposes of interviews and discussions during my visits. My next visit was to the level 3 NICU at the Osaka Women and Children's Hospital, also a hub for the Neonatal Mutual Co-operative System (NMCS). In Osaka I also met with Professor Hirano, director of the NRNJ, also representing the Osaka Research Institute for Maternal and Child Health.

The second leg of my fellowship, to Canada, included visits to units of the neonatal service in Toronto, predominantly Mount Sinai Hospital's level 3 NICU. I met with representatives from surrounding neonatal services including McMaster Children's Hospital, Sunnybrook Hospital and The Hospital for Sick Children "SickKids", as well as further afield Canadian services including IWK Health Centre in Halifax, Nova Scotia. I visited and worked with teams at the MiCare facility for Maternal-Infant Care, under the umbrella of the Canadian Institute for Health Research, the EPIQ quality improvement team, and the Canadian Neonatal Network base in Toronto. I was fortunate to attend the international EPIQ annual conference during my stay in Canada.

3.0 The What – An International Exploration

This project took place with a backdrop of active and important conversations in the UK concerning the “threshold” gestations and broader circumstances in which we might, could, and should offer intensive care with a focus on sustaining life versus a palliative comfort focus.

This project does *not* propose to specifically address these ethical dilemmas, to advocate a particular “threshold viability”, nor adopt a particular stance in this complex debate. This work sought instead to **identify best practices, and aspirations for excellence in care, in supporting those babies and families who are to receive intensive care with a life-sustaining focus.**

3.0a Value and Quality in Neonatal Care

I sought to identify best practices with consideration of both quality and value (Figure 1). Japan, in part, and Canada both have publicly funded health care systems and offer neonatal care without the possibility of charge to the family. With the NHS in mind, identifying interventions or strategies with prohibitive financial implications would be of limited value to our services. That said, better quality care by any reasonable metric achieving improved outcomes for EPBs will almost certainly be more cost effective for health and social care in the long term.

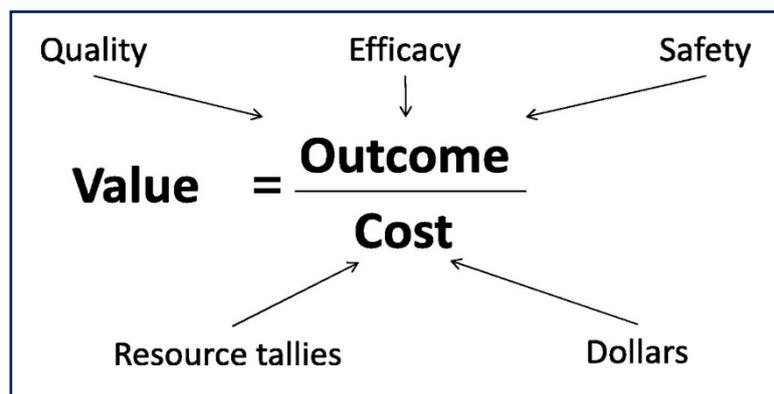


Figure 1: A representation of the key pillars interconnecting value, quality and outcomes in healthcare, key to working in QI ventures [Dukhovny; 2016]

3.0b Survival at extreme viable birth weight in Japan: Timely press coverage

As I returned from the first leg of my fellowship, international press coverage of two extremely premature, extremely low birth weight “micro-preemies” emerged. The two baby boys, both born in Japan, weighing less than 300g, had survived to discharge with few commonly encountered serious sequelae for their stage of development. Baby Ryusuke was born weighing just 268g - one of the smallest known weights for a surviving infant worldwide (Image 2). His contemporary from Tokyo weighed 258g at birth. Coverage from Japanese NICUs described the remarkable progress in Japan caring for such babies and the immense pride from the professional healthcare teams in achieving positive outcomes for a “happy long life” for the babies and their families.



Image 2: UK press coverage from The Mirror of the Japanese baby boy from Tokyo, birth weight 268g at 24 weeks “similar in size to a packet of butter”.

The coverage concerning these babies beautifully aligned with this fellowship; a timely illustration of the outstanding achievements possible in the most specialised Japanese NICUs. I had been fascinated and delighted to learn about these cases during my fellowship – three such EPBs had been delivered during my visits, and I had been privileged to witness care of many more during their admissions.

3.1 Japan

3.1a Places & Policies

National Centre for Child Health & Development Tokyo – NCCHD



Image 3: National Centre for Child Health & Development, Tokyo, Japan.

The NCCHD resides in the greater Tokyo area (Tokyo city-prefecture) comprising a clinical hospital, research institute and centre for child development. Their philosophy of practise is to pioneer cutting edge innovation and technology, promote research in child health, and develop and nurture specialists for the future. I visited the Center for Maternal-Fetal, Neonatal and Reproductive Medicine, home to a level 3 NICU caring for surgical, cardiac, and complex fetal medicine cases on a referral basis.

Osaka Women’s and Children’s Hospital: OWC

“We sincerely hope that mothers, children and their families are spending every day with a smile”

The above quote is the founding philosophy of OWC. The organisation describes a key aim for their HCPs and patients to trust one another in giving and receiving medical treatment. OWC works within the wider community to optimise professional relationships with health and welfare bodies. **Neonatologists follow-up their fragile patients, including EPBs, to 9 years of age – a vast contrast from standard UK practice; follow-up to 2 years.** I was intrigued in the potential impact on clinicians of such sustained and long-term feedback. What might change in our own practice if we followed our patients as they graduate from nursery, transition to middle school and experience the challenges of maintaining peer friendships and developing in education?



Image 4: Osaka Women's and Children's Hospital entrance, Osaka prefecture, Japan.

The OWC neonatal service has among the lowest mortality for EPBs in Japan. OWC is a key player in establishing and evolving the Neonatal Mutual Co-operative System (NMCS) in the Osaka prefecture, a body with parallels to UK operational delivery networks (ODNs). First established in 1977, 6 “base hospitals” collaborate with 9 “sub-base hospitals” to review and optimise perinatal care. Active projects include optimising neonatal transport, implementation of “scenario based neonatal resuscitation training”, and collaborations with emergency services.

Survival of Extreme Prematurity and NRNJ

The Neonatal Research Network of Japan (NRNJ) is responsible for much of the Japanese academic output pertaining to EPBs. They recently evaluated data from 31,000 infants born between 2003 and 2012 (Nakanishi *et al.*, 2018) identifying downward trends over time in mortality, significant motor impairment, home oxygen use and neurosensory disturbance; vitally reassuring findings. It has understandably been speculated that where survival increases, these lives may be saved at the cost of increased neurodisability. For this important dataset, this was not the case.

End-of-life care

I heard from numerous physicians that withdrawal of intensive care is “not lawful in Japan”; the law and its interpretation are in fact complex. I heard eloquent explanations of the “profound difference” in attitudes to life-sustaining versus palliative care between Japanese and Western neonatal practices. I learnt of the Japanese Ministry of Health, Labour and Welfare “**Guidelines for decision making process end of life care**” in 2007. These reference lawful end-of-life decision making based on informed consent by the patient or family, withdrawal of “aggressive treatment” as determined by the healthcare team, and utmost importance of “sufficient relief of discomfort”.

Despite the existence of such guidance, HCPs have been prosecuted regarding end-of-life decisions terminating life-sustaining intensive care. Only more recently have cases been brought to public attention where reorientation to comfort/palliative care have not seen prosecution or judgement. There is still a firm reluctance, or refusal, to withdraw or reorient intensive care among many Japanese neonatologists and trainees still incorrectly consider this not to be an option:

“There are no circumstances in Japan where this is okay. We can withhold, or can limit the care we start, but once it has started, we cannot legally withdraw it away again”

It was thus even more intriguing that survivors of extreme prematurity do not have a greater burden of neurodevelopmental impairment than in the UK. What aspects of care for these tiniest babies are stacking the odds in their favour?

3.1b Practices and principles

It would be impossible to describe every practise of interest observed in Japan, nor would I attempt to do so here. A few categories of clinical care were of particular interest and may have the greatest potential gains for the UK:

- Care in the first hours of life
- Neuroprotection and neuropromotion
- Infection control practices
- Gut health and breast milk

Allied areas which struck me as key to effective care delivery were:

- I.T. infrastructure and utilisation
- Workforce make up
- Culture, climate and “Ikigai”

The first Golden Hours of life

The “Golden Hour” in Neonatology represents the goal of very early care for very early babies. Completion of stabilisation, admission to NICU and all vital procedures within a timely period from birth facilitates early stability and minimal disturbance thereafter. Principles of early care for EPBs in Japan are **experienced leadership, expedient procedures and stabilisation is undertaken in the delivery room**. Teams comprise 2 or 3 senior neonatal doctors dependent upon time of day (only 2 doctors are resident at night) and procedures as well as team oversight are commonly performed by consultant equivalent “Staff”. Umbilical cord milking is routine practice in Japan, in contrast to the increasingly prevalent “delayed cord clamping” (DCC) practised here. Clinical care and procedures are supported by maternity nurses (midwife equivalents), releasing NICU nurses to meticulously prepare the incubator, ventilator, drugs and infusions required on admission to the unit.

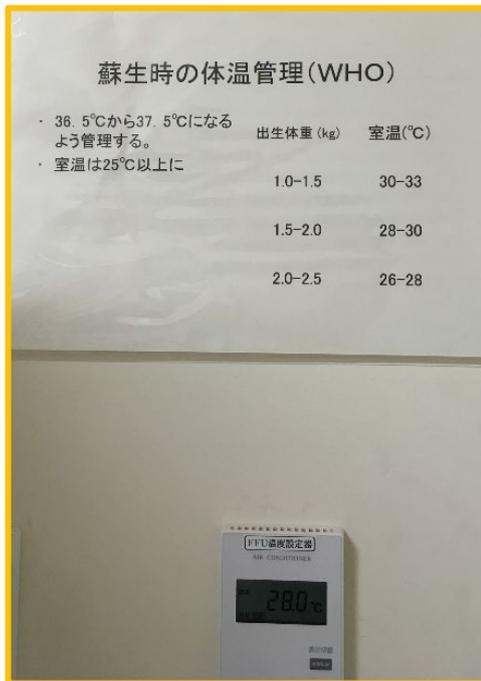


Image 5: An example of making it easy to do the right thing; A prompt for delivery room temperature based on anticipated birth weight, sited immediately above the room’s thermostat. Infants below 1kg have a room temperature goal of 33 degrees.

Contrary to common UK practice, after endotracheal intubation and surfactant administration, vascular and imaging procedures are also immediately undertaken by senior practitioners. I observed percutaneous central lines “long lines” being inserted by team members within the first half hour of life, with normothermia being supported by a room temperature of 30-32 degrees, far higher than my UK experience. **Umbilical lines have no place in routine early care.** I heard a great deal about the firmly held belief that umbilical catheters represent 2 significant risks: compromise or disturbance to gut blood flow and perfusion, and a significant infection portal. EPBs typically have their first ultrasound scans (USS) in this early phase also; cranial, cardiac, and abdominal scans would be typical. This is facilitated by the expansive experience of all neonatology fellows and Staff in scanning infants.

A tremendous difference among all but the smallest babies, was the time made to ensure skin-to-skin or kangaroo care before admission to the unit. It is not uncommon for mothers and fathers worldwide to wait days or weeks for their first cuddle, despite benefits for baby and parent from achieving early positive touches and holding (Campbell-Yeo *et al.*, 2015). Once initial stabilisation has taken place, during preparation for transfer to the NICU, the **EPB is gently placed into skin-to-skin with mother, paying meticulous attention to security of tubes and lines.** The ethos underlying includes the emotional positive impact for families, but also beneficial maternal flora from close contact at this earliest stage, and the strong potential benefits for early breast milk production.

Neuroprotection and Neuropromotion: The Holy Grail

The 1st 72 hours “The acute phase”, was a time of exceptional team focus on protecting the EPB brain from IVH and brain injury, ensuring stable physiology as far as possible, including an extremely minimal handling approach. The rate of severe brain injury below 32 weeks is around 6-8%, closer to 10% in the smallest EPB cohort. There is widespread use of prophylactic indomethacin treatment to reduce the risk of brain injury: below 25 weeks, indomethacin planned for the first 3 days of life. Exploring

this with Japanese physicians, they consider the **benefits may be pronounced in their hands due to intensive cardiovascular monitoring and frequent USS imaging of heart and brain**. In house research and local academic projects on the NICU were common, a local project had explored the changes in internal cerebral vein flow patterns in attempt to pre-empt and prevent IVH (Ikeda et al., 2015). Recently publishing their findings, the team were passionate to identify predictors of significant IVH and enhance their ability to prevent. Rather more than any particular technical element, I was impressed by the prevalence of hands-on clinical research in each NICU. The ethos of utter commitment to understanding pathophysiology and measures to ameliorate important diseases for EPBs, was clear and defined.

“Japanese babies are inherently smaller aren’t they? Tiny babies would do better.”

There is a common perception that children in Japan are smaller in stature than the UK, and so for any given gestation babies’ birthweight would be lower. The logic follows that “miraculously small” babies can survive in Japan because at any given weight they would be more mature than UK counterparts. Whilst growth charts (centile charts) are different in their design and interpretation, growth profiles and local charts were shared with me to generate these data. No – babies in Japan are not smaller as a population (Figure 2).

	GA (weeks)	9/10th (Growth centiles)	Med	90/91st
Japan	22	443	507	558
	25	619	784	976
	28	1038	1156	1379
UK	(24	510	700	800)
	25	600	775	950
	28	780	1170	1430

Figure 2: Birth weights in grams collated for 9th, median & 90th centiles (Japan) compared to 10th, median & 91st centiles (UK) for male infants at 22, 25 and 28 weeks gestation at birth.

Gut health and infection prevention

Reducing the risk of infection for EPBs is highly prized and gut health is promoted hand-in-hand with infection control procedures. I would go so far as to say infection control was a prominent part of unit culture in the services I visited. I was politely, humbly, but clearly challenged by staff more than once if I wasn’t quite complying with the strict local protocols. **Overall units are designed to make it easy to the right thing - I have mentioned this before and will again.**

As shown in figure 3, measures span from team arrival at work, through the entire journey of the NICU. All staff wear clean NICU scrubs and/or white coats strictly for the unit, with lockers and

changing spaces available for the beginning and end of shifts. The entrance to one NICU had a complete antechamber in which all entering would scrub their hands to the elbows on first entry, and hand wash for a full minute on subsequent entries. A timer could be seen by every sink to support completely normal practice of handwashing for the correct time. Posters and images had been designed to clearly highlight and remind staff of the common “risk areas” such as donning and doffing aprons or gowns. I heard from nurses that this was not infantilising or patronising but just perceived as a reminder.

“We all can forget the important things which seem small when the unit is so busy. We can be helped to do a good job for the patients by seeing the notices sometimes”

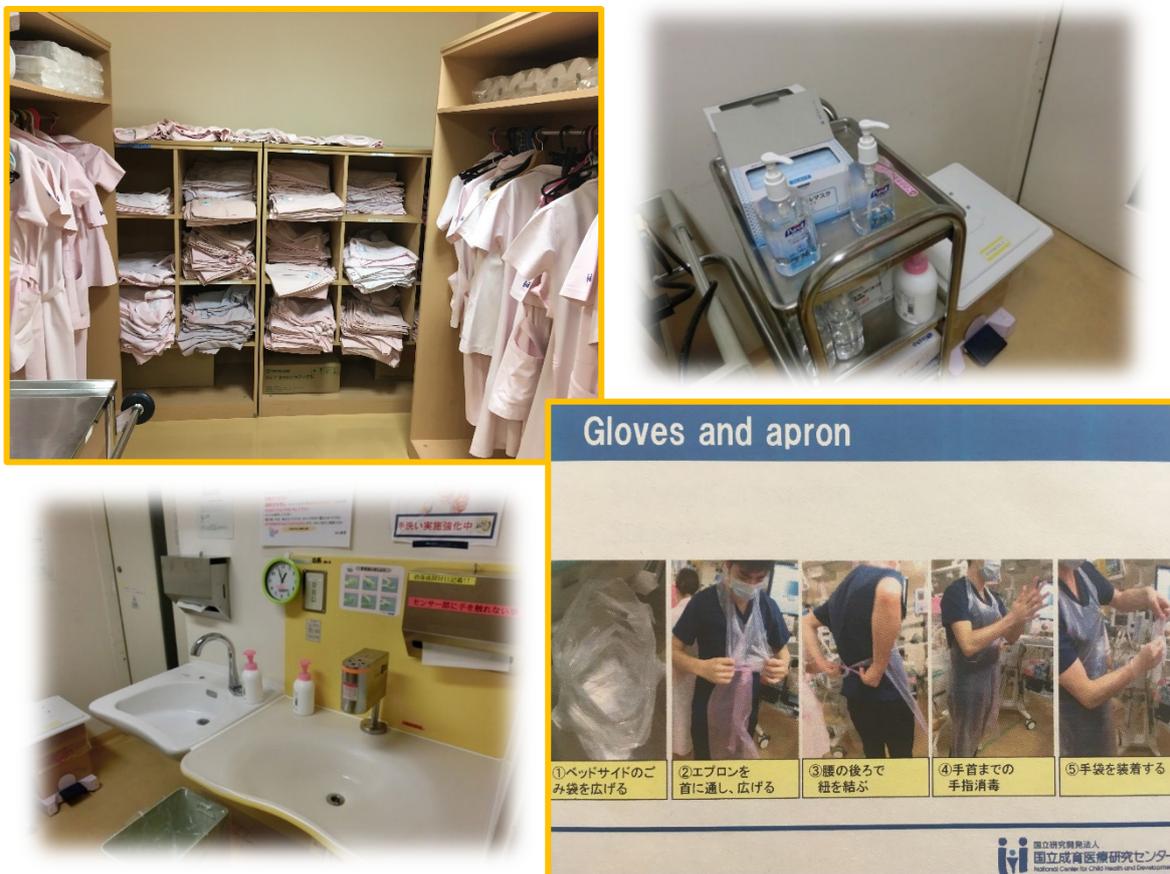
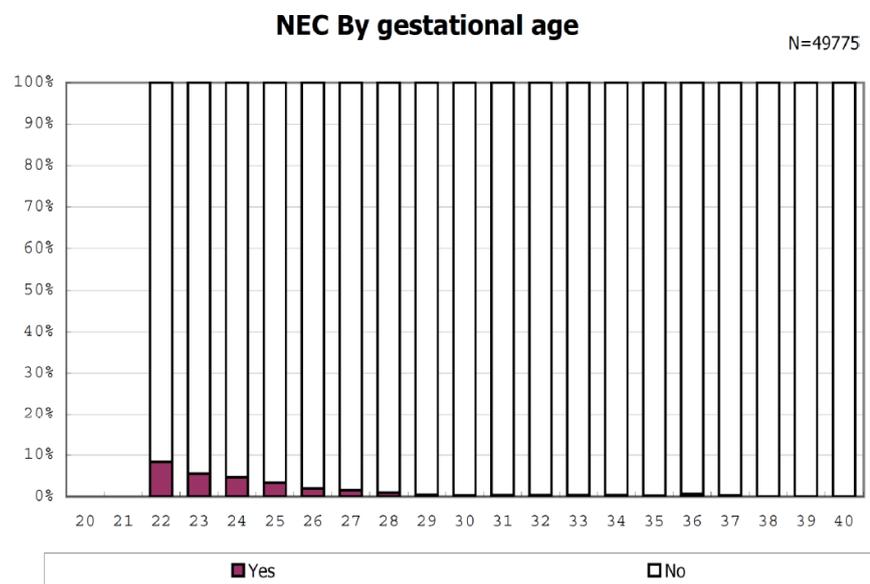


Figure 3: Infection prevention and reduction measures observed: uniform wardrobe and changing area (top left), hand and personal hygiene station example (top right), entrance antechamber hand scrubbing area (bottom left), instructional reminder poster e.g. applying apron and gloves bottom right).

Maternal breast milk expression was supported antenatally, and immediately after birth, guided by maternity nurses. 99% of Japanese NICUs strive for “zero formula” and I heard that perhaps 1/3

have a formal milk bank operation with access to pasteurised donor milk. I heard about the relatively **common practice of milk sharing on units, with mothers consenting for excess expressed milk to be used for babies awaiting their own maternal milk.** Colleagues understood that western practitioners may see this as an unacceptable practice, not appropriate for modern care. Mothers are subject to microbiological screening of blood and breast milk and share an understanding of potential benefits of fresh milk versus risks of formula or potentially pasteurised milk. Clinicians told me the risks from fresh milk sharing are not, at least currently, so significant as to outweigh the potential benefits. Japan experience world leading rates of low NEC incidence (Figure 4). When I asked several practitioners why, I heard “fresh milk” “breast milk” “our milk practices” over and again. Other common responses were the strict attention to general infection control such as regularly swabbing equipment e.g., incubators, and careful and deliberate antimicrobial stewardship.

Figure 4: Renowned extremely low rates of NEC among NICU admissions (NRNJ data, shared with permission)



IT infrastructure & tools

I witnessed a tremendous variety of digital solutions to common challenges faced in the NICU. This complimented the strengths and limitations of the human workforce. Discussing tasks or roles performed by the spectrum of HCPs... **“You know the computers do that.” “We don’t have people for that here.” “I think computers may do that better”.**

Elegant I.T platforms were commonplace, some home-grown solutions by local clinician-technician teams, though commercially available digital platforms were more common. A frequent platform set up would include a PC and two monitors by each cot space in ICU, exclusively for the care and administration associated with that patient. This would facilitate electronic smooth running of operations and tasks commonly including:

- Listed tasks and “orders” for the patient day, updated from handover, colour coded by planned, pending, in progress and completed group labels.

- Digital prescribing and drug ordering with barcode supported tracking/administration.
- Each prescribed item's preparation instructions, compatibility profiles and potential interactions with other treatments available at a single click.
- Collated data from drug/infusion pumps, milk barcode information (type, volume, time scanned to administer), monitor trends over time, integrated radiology reports and laboratory results.
- Single click linkage to maternal details and clinically relevant medial information.
- Electronic note keeping for all HCPs at the bedside, or remotely at a separate terminal.
- Shift handover summaries automatically generated according to locally set preferences.
- Integrated data collection for key metrics to be submitted externally and/or for local governance perspectives, also directly linking to clinical coding equivalents.

Estimates from **local data suggested a saving of 2 hours nursing time as a minimum per shift, versus the previous systems of checking, note taking, calculations and documentation.** In the ICU areas one nurse may be responsible for 3 babies, working in a buddy system. It was notable that such a significant amount of time had been freed up to deliver care directly to the family that time pressures were removed for key tasks such as supporting kangaroo care, devoting sufficient time to medication preparation, or peer support and training. The younger nurses I spoke with found it difficult to conceptualise a system of documenting observations from a monitor or ventilator onto a paper chart.

Medical Workforce

Among the NCCHD team (Image 6) each consultant equivalent “Staff Neonatologist, or Staff” had a particular interest or area of expertise for which they contributed to service development and/or research. Staff colleagues’ areas of interest and skill reflected some similar coverage to that commonly seen in the UK, and some diverse roles:

- Nutrition, lactation and breast feeding support
- Haemodynamics and cardiovascular support
- Neuroprotection, neuropathology and IVH research
- Respiratory physiology, ventilation and non-invasive support
- Infection surveillance, prevention and reduction

To link with my prior discussion of I.T. in the NICUs, this had a direct impact on medical working, experience, and training. When initially comparing team sizes common in the UK versus Japan I was surprised by the compact teams and yet positive training reports; unpicking the digital resources available, many of my questions were answered. For an NICU with more than 40 patients, 7 junior doctors in total worked on a day to day basis, typically 1 or 2 doctors away from the hospital after being on-call. An average of 4 juniors worked in fluidity with the Staff covering the NICU, SCBU/“growing care unit”, attending the extensive list of deliveries for which a medical practitioner is required, perform all routine newborn examinations, and conduct follow-up out-patient appointments. This somewhat overwhelming list of responsibilities and roles combined with just one week of formally

recognised annual leave per year should be insurmountable; surely a recipe for physician burnout? In the context of the institutions I visited – it was seemingly not.



Image 6: The medical team at NCCHD; Lead Clinician (front left facing), Staff Neonatologists, Fellows, Residents and one of the pharmacy team present for the preceding meeting

The culture of the teams, support of the seniors, close working with nurses and undoubtedly the huge contribution of digital technologies made the job not only manageable but enjoyable. Trainee level doctors told me of the huge pride they took in their profession, the satisfaction of what they do **“truly mattering to families”** and their commonplace engagement with research and publications as **“fulfilling the brain as well as well as the heart”**. Whilst I certainly had concerns as to work-life balance for these young, bright professionals, they seemed to savour the continuity of care their work pattern provided for the babies and their professional development.



Image 7: Down time at NCCHD – I learnt lunchtime origami, and my yellow origami heart can be seen halfway up the tree – an annual December tradition accompanied by local school children singing and dancing, and a ceremony of bell ringing.

Ikigai 生き甲斐

“Why do you think the outcomes here are so good?” I asked the most experienced professors, nursing colleagues, junior residents, rotating fellows... As expected, there was wide and interesting variety in responses. Nurses were extremely humble overall and more likely to reply “we’re not so different from other units... it’s just good fortune... the doctors work very hard...”. Trainees commonly expressed that nursing care was of an exceptional standard and this was of tremendous value. There was one fascinating recurrent theme; it can be summarised as “Ikigai”.

“This is a calling; we have an absolute responsibility to these babies and families.”

“This isn’t just a job for us,” said one professor from OWC, describing his belief as to the excellence and continued improvement of the unit’s outcomes, “...this is a calling, we have an absolute responsibility to these babies and families.” He explained the deep personal engagement neonatologists have with the service they provide. “I can’t imagine the way other countries’ doctors hand over so frequently. Surely that diffuses responsibility?”

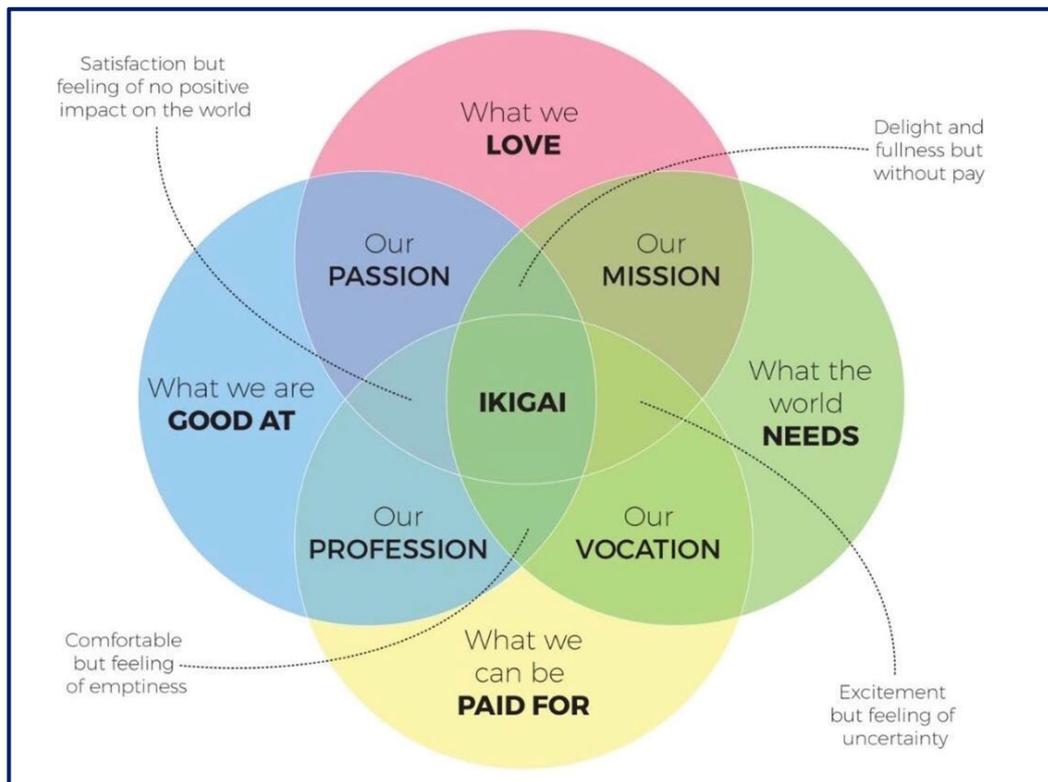


Figure 5: The principle of Ikigai “The key to a long, healthy and happy life”.
Original source: Dreamstime.com [creative commons].

His posture when he described this Japanese way of being was inspiring, calming and eloquent; the essence of Ikigai (Figure 5). The meeting of one’s professional training and skills with one’s passion for their profession creates true satisfaction from coming to work and playing that role. The interlinking of that trained profession with being paid, and relative security for the future, leads to a comfortable and peaceful feeling meaning doctors rarely leave the profession. Recognition that the world needs us as professionals and that we can earn a living from something benefiting the world so greatly is an exciting and fulfilling concept. The overlap of vocation, passion, profession and mission in a Venn diagram of contentment, excitement - reason for being – this is, albeit tremendously simplified, Ikigai. **This, I heard time and again, makes neonatology in Japan different. It is special.**

3.2 Canada

3.2a Places & Policies

The Canadian Neonatal Network – CNN

This group of collaborative researchers was founded in 1995 and now comprises 31 tertiary NICUs. Numerous Canadian universities also contribute to the research output of the network. The network's mission statement is concise:

“To conduct leading multi-disciplinary, collaborative research dedicated to the improvement of neonatal-prenatal health and health care in Canada and internationally”

- Annual Report

31 NICUs contributed data to the 2018 annual report (close to 15000 patients, over 4000 babies <32 weeks, almost 1700 <29 weeks). Clinicians and researchers who wish to access this data for local or comparative research questions can do so free of charge. The UK model has charges associated with comparable data access for reasons pertaining to database maintenance. Whilst this makes sense for the current UK system, academic output from the CNN system is significant.

Evidence-Based Practice for improving Quality – EPIQ

The EPIQ programme, led by the humble and prolific Professor Shoo Lee, was born from important lessons learned from experience of the Vermont-Oxford Network (VON), a U.S. based neonatal improvement network. Professor Lee described the rationale for the project, its iterations and movement forwards. VON had, to date, been unable to demonstrate more than minimal effects on outcomes for NICU infants. One possible conclusion was that improvement goals were based on “intuition & anecdote, not evidence” (Lee, S. *et al.*, 2014). EPIQ is thus underpinned by:

- **Use & application of published, available, high-quality evidence**
- **Hospital specific data to generate targets for improvement**
- **A national network for collaboration; sharing experience & expertise**

The primary research concerned 12 CNN hospitals from 2002 to 2005, half randomised to reduce nosocomial infection (healthcare associated infection/NI), half to preventing bronchopulmonary dysplasia (CLD/BPD). Interventions included face-to-face critical appraisal workshops for site investigators and MDT teams formed with shorter skills workshops offered to all team members. Each hospital developed a specific list of practice changes and priorities based on their in-house data. Teams were supported to intervene with PDSA (plan-do-study-act) improvement cycles of 1-3 months in length, using diverse communication strategies to engage and update the wider teams.

Figure 6: The pillars of EPIQ – Plan Do Study Act methodology, the EPIQ 10 steps for planning and execution of projects and improvement cycles, key principles of Information, Collaboration and Implementation.



Of vital importance was the detailed method with which sites selected their precise interventions. **The programme facilitated granular examination of local data** such as the precise timing of the most common CLABSI (central line associated blood stream infections) for that unit. Depending upon the peak time for infection events the local team could focus specifically on either line maintenance protocols, line insertion techniques, or infection monitoring methods. These are key aspects of the difference between EPIQ methodology and others employed commonly to date. Figure 7 demonstrates the improvements in outcome seen as the programme evolved and progressed.

EPIQ Evidence-based Practice for Improving Quality

Measure	2013 to 2017 change (Odds ratio, 95% CI)	P value
Mortality or major morbidity	0.72 (0.61, 0.84)	<0.01
Necrotising Enterocolitis	0.66 (0.49, 0.89)	<0.01
Nosocomial infection (26-28w)	0.64 (0.49, 0.84)	<0.01

Figure 7: Improvement outcomes for the EPIQ research programme (2013-2017 iteration), demonstrating significantly reduced mortality/major morbidity, NEC and nosocomial infections among groups targeting care improvements in NICU among preterm babies.

- Sharing & Peer Support

Methods and support structures for sharing QI are evolving in the UK. Bodies such as the BAPM Quality Collaborative are beginning to offer signposting, tailored resources and guidance towards conducting effective QI specific to neonatology. Services I visited in Canada had identified opportunities and solutions to expand and explore every opportunity to learn.

One of the most valued aspects of the EPIQ programme is site-swap visits. Practitioners from NICUs targeting the same overall quality outcome e.g. BPD reduction, visit one another's institution to share problems, lessons learned and key approaches to interventions. It's challenging to articulate the precise benefit of this adjunct in the complex adaptive system of healthcare. I met with team members following their reciprocal visits; "We try to match with units on a few factors rather than just the target for our improvement. A unit doing great at "x" is really important but more so also, is that they match us for population, culture, some demographics... the stuff that often times people will say – yeah but our results are bad because... we try to really avoid the traps." Translation of knowledge has been considered in great depth (Cronin *et al.*, 2015). In practice, visibility of results and feedback to hands-on clinical teams was highly valued. Teams told me about feeling they were "authorised" to make effective small changes and the empowerment this enabled.

"We try to match with units on a few factors... that they match us for population, culture... stuff that often times people will say – yeah but our results are bad because... we try to really avoid the traps."

Innovations in kit and technology were rarely the solutions - people and process are master here. The social and organisational factors of an institution had a greater impact on project success than policy. Leadership, much discussed, was described as the gatekeeper to the goals. A local leader with passion, sincerity, and the ability to create an appealing vision of the future for the team was the greatest intangible – difficult to quantify but the holy grail for research teams.

3.2b Practices – observation and evolution

Care Menus & Bundles

Teams use a consensus approach to identify which practice changes map most closely to their needs based on best available evidence. This depends on the availability of site-specific outcome data, of sufficient quality to trust. Bundles or menus of evidence-based interventions are now developed by panels nationally. These national "Evaluation Groups" work on specified themes e.g. brain health, gut health, lung health, each group with 2 co-leads who may be doctors or AHPs from neonatal practise across Canada. The groups review published evidence in their field annually "It makes you own it, you know", I was told with a beaming smile by an RT (Respiratory Therapist), **"...if you've been a part of evaluating, understanding, the data that's out there then you can actually put together options and choices that make sense. You can know what we don't know, you know?"**.

Local QI projects are thus tailored to specific metrics and honed as far as possible. Rather than imposed or broad problem solving I heard:

“...we have a problem with severe BPD among our really tiny babies. Our sentinel case reviews look like these are the babies we’ve been extubating real early. So we’ve worked on a bundle how to best do respiratory support for micro-preemies... along the lines of when we should stay intubated for a little longer, how to do it.”

The sense of investment in these projects was exciting. It was one of those experiences that made me want to get back to my own team and show them what was going on out there.

The role of the peer champion

Most commonly, but not exclusively, peer champion was a role held by nursing colleagues. I explored how it was possible to sustain enthusiasm, and enough knowledge for a large number of changes. Some staff reported “It isn’t. It’s far too many things at once”. Others felt that with peer champions available for every active project, it was sustainable. **Teams described tangible benefit from these “resident experts” having a deeper, more comprehensive understanding and training in their “specialty project”,** acting as a training resource, taking great pride in education development. Some had developed posters, flyers, presentations and best practice videos to support effective education. I was able to summarise 2 key themes:

1. Empowerment in action matters – permission to develop resources, train one another, modify teaching content in “real-time” and have the authority to effect necessary changes was a huge driving force in moving projects forward, trouble-shooting their roll out and sustaining momentum with their embedding into standard practice.
2. Relationship building effects change – these champions support the translation of knowledge and theory of a project into competencies and capabilities. This happens because of the relationships; the resources in and of themselves are not enough. Enthusiasm, passion and credibility matter to the successful integration of proposed improvements.

Barriers to implementation and sustained change

Theories on barriers to change implementation are well published. What are the perceived day-to-day barriers which stop us from doing “*the right thing*” on a regular basis even if we would like to? I explored this question with clinical teams in both Canada and Japan.

I heard about the challenge of effective translation from evidence, to ratified guideline, to real improvement. Even projects with clearly defined paths had fallen at implementation with little ownership by staff “Nowhere near enough trainers to help make it happen, sometimes people come to work and don’t even know about the new thing.” When so much healthcare provision stems from goodwill and motivation of dedicated staff it seems logical that projects unsupported in day-to-day execution will fail and become “whatever happened to...” examples.

Consistent senior practice was mentioned time and again with respect to project hurdles which became “insurmountable”. Teams described their empathy for senior attendings, consultants and highly skilled other professionals in limiting their professional autonomy by “enforcing” a unified guideline upon them. However, a lack of consistency in the approach of clinicians was described as “...tying their hands with respect to improvement”.

Where beliefs and strategies of seniors were demonstrably at odds with one another, guidelines and bundles were not followed. Teams described the impact as a loss of direction and a failure to believe in one direction of travel for the team. The insightful descriptions in no way suggested that all patients be cared for by rigid, rote guidelines. Rather I heard from eloquent nurses, junior doctors and allied teams that a predictable lack of consistency eroded any belief in the bundles or standards of practice described in that institution.

“...if they don’t believe in it, maybe it’s just not right. It probably doesn’t matter if we don’t do things like that”.

3.3 The Parent Perspective

During the fellowship, I was privileged to undertake several unstructured meetings and semi-structured interviews with parents of NICU infants. Full and informed written consent was obtained from a selection of mothers with lived experience of neonatal care, who expressed a desire to share stories of their babies' care. A number of these families shared photographs and heartfelt personal experiences which they consented to be shared specifically for the benefit of learning from this project.

Experiences included those of Karen, a mum who had experienced a "high risk" complex pregnancy after several devastating prior losses. Karen's baby received 87 days of NICU care. Shelley, a nurse, delivered a baby girl extremely preterm. Their family had a protracted stay across multiple neonatal units and services. Kiran shared her experiences alongside her extremely low birth weight premature twins, one suffering more extensive complications of prematurity than the other. Kiran and her babies experienced multiple care pathways including ex-utero transfers to a tertiary service, having been "outborn" in a local neonatal unit.

The families I engaged with told their personal stories before focussing on some discussion around their experiences of QI, either during their NICU stays or since. We explored the themes of improvement work which they considered important and valuable, and how they felt families best contributed, or could contribute, meaningfully to this work. Mothers expressed the key areas in neonatal care they thought were ripe for QI focus and gains. I cannot encompass the full richness and depth of their inputs and experiences in this report. I attempt only to collate the prominent themes and key points for this summary document.

3.3a Peer support

"Our hospital went to such lengths to protect babies' privacy, that they isolated the mothers from one another."

I heard time and again that feelings of isolation and lacking peer-to-peer support were detrimental to families' care, a prime target for QI efforts. I heard how the language used, by professionals, the positioning of chairs on the NICU, drawing of curtains around mothers for kangaroo care... all impacted profoundly on the parents' sense of isolation from others. "Would I be breaking the rules to talk to another mum?".

"I just wanted to talk to someone who had been there, done that. I made it, I'm here on the other side. I understand that not everybody needs that though."

QI efforts concerning peer volunteers on the NICU had been extremely well perceived. One mother, Karen, had become a peer volunteer, champion and advocate since her experience of neonatal care with her son. **The provision of a programme to embed peers who had "survived NICU" was seen as a project of great value**, complementary to services and support offered by psychology or social work.

Please join us at Snack Chat for the opportunity to learn more about your baby and their particular needs. It is also a great chance to meet other families who have babies in the unit. All are welcome, including parents, family members and other supports!

Open to all parents and supports currently in the NICU

Each session run by NICU team members and a graduate parent.

Thank you to the Canadian Premature Babies Foundation for supporting our snack chats!



Image 8: “Snack Chat” a peer support intervention co-led by Karen, a graduate parent from NICU. Developed within a programme of QI supporting parent advisory, leadership and volunteer roles.

Image 9: Parents’ craft outputs from peer-peer support groups instituted within a level 3 NICU’s QI programme for parent support



Mothers in units lacking formal peer-peer support mechanisms, where they described feeling alone in their grief for a “normal pregnancy & baby”, were sometimes encouraged to reach out through social media for support. The experience was too commonly one of isolation “encouraged” on the NICU for the purposes of privacy, a well reported and published phenomenon (Hagen et al., 2019). Support groups in a specific region or institution were often mentioned to families but not specifically encouraged or clearly signposted. Research strongly suggests that **to meaningfully engage patients or parents in improvement ventures, we must first support a positively engaged, supported and nurtured experience during their episode/s of healthcare** (Celenza et al., 2017).

“There wasn’t a tonne of information up and around the units, which I think actually would be beneficial, because I mean I would read it to learn more about these things even if it’s a basic little poster in layman’s terms.”

3.3b Staff relationships with family

Effective relationships between NICU teams and parents are the foundation of any future possible engagement with QI. Parents perceiving a relationship of empathy and respect are far more likely to have an overall positive experience of their NICU journey (Hagen *et al.*, 2019). From my interviews, a huge component was the calibre of communication between staff and parents, from the very first interaction, through to discharge planning and transition home.

***“I’m sitting there and the babies are gone...
I have no idea like what’s gonna happen next”***

Kiran described intense emotional distress at the point her twins were transferred, without her, to a level 3 NICU in their region. Though the transfers for intensive care were clinically appropriate and warranted for the babies’ care, **her recollection is clearly that communication around the time transfers merits consideration for improvement.** I never had an impression that the families speaking with me were anything less than intensely grateful for their children’s care. My sense was rather that at points in their journeys there was desperation, anxiety and fear which could be addressed, and potential improvements in support and communication made to services globally. Consistency in parents being universally welcome at the cot-side was being “worked on” in many places. “One nurse who was quite a senior nurse – we had a poor experience at first – she didn’t want us staying there when Hailey was quite unstable. We were made to feel unwelcome where we *had* been encouraged to stay whenever we wanted.”

Where parents perceived the most challenging relationships with teams or individual caregivers, they described feeling insecure to leave baby’s side. I heard about distress and discomfort when having to leave the unit; “My baby felt like she was put on the back burner. It felt as if she didn’t get as much effort.” An equity of care, time and perceived favour among babies was a key area for improvements in unit culture according to parents. One service had developed a thoughtful and comprehensive intake questionnaire as part of their improvement journey. “Tell us about your family...” Mothers described feeling empowered and released to share previous losses, miscarriages, traumatic pregnancies, their fears for their family and this precious baby. **Being able to express their intense fear at losing the baby in front of them, felt that it enabled caregivers to better understand and support them in times of stress.** A further step included needs assessment questionnaires, developed by graduate parent panels supported by professionals “If you don’t feel adequately supported, what might you like, how will we know, when should we address this...?”

***“No one was there until Monday morning.
Furthermore, I was always the one giving my husband bad news.”***

A huge area for potential consideration in our services, was timely availability of professionals for family updates, “The NICU experience [for families] isn’t 9 to 5, babies do NOT respect these hours when being born or admitted!”

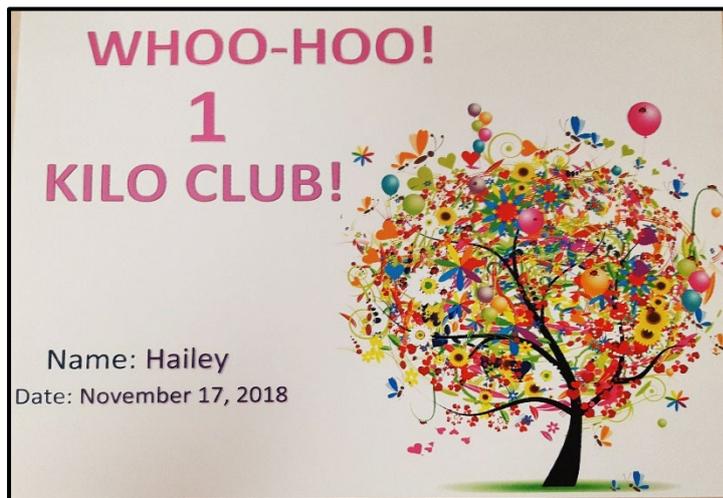


Image 10: Celebratory communication milestones with families. “Every milestone, every baby, every time” demonstrating baby Hailey’s long awaited membership of the “One-kilo club” proudly presented to her parents

3.3c Improving clinical care

“The process of transferring hospitals I found a little bit stressful. They don’t know when you can go, and then – you’re gone! The transition process – there are definitely opportunities there, you know even if it’s just someone greeting you there”

The process of transferring infants between hospitals, common practice in neonatology was a clear and recurrent focus for QI opportunities. Where parents recalled detailed and timely discussions about the risks and intended benefits of transporting their babies, the stress associated with this episode was described as much reduced “She had a further small bleed [in her brain] and the team were open to discussing that could have been related to transport. The risks had already been fully discussed with us [of transferring her] but they also explained where there were really no alternatives. They were very good at teaching us about it.”

Consistency of care, most pertinently consistency of lead clinicians and nursing teams, was high on the improvement agenda. The concept of having a “primary team” and the process of working towards this, was something mothers were highly motivated to support. They expressed huge empathy for staff shortages and challenges but saw the benefits of a “core group” caring for their baby and family as beneficial for the whole team. This would further support the long-term involvement of some families in QI either during or after their admission. **The desire for parents to feel more beneficial to their children came through loud and clear.** Where FiCare is not prominent and parents lack encouragement to be key or primary carers for their baby on the NICU, there are real gaps for service improvement. I heard one mother’s yearning to feel important and helpful to her baby girl.

“Little things parents can maybe feel like maybe they’re benefiting... this is a way for ME to help my baby. There were so many times I was in there and I felt so helpless... even just like those little extra things that might help with her development... little things that you would pinpoint how I can benefit my baby so that she has the best possible outcome.”

3.3d Parents as Improvement partners

Countless Canadian units were delivering safety huddles in their NICU, as is increasingly common in the UK. The degree to which these huddles and improvement projects are actively engaging parents as partners varies tremendously. Some descriptions were of local QI being “only for the NICU staff” in such a way that it was based on “acronyms and unintelligible conversations”.

“Parents duck through the [safety] huddle and try to get by it. It’s for the HCPs to look at...”

Understandable reservations were voiced as to potential pitfalls in parent input to improvements. Knowledge of the ways a unit was not meeting its targets or was poorly benchmarked relative to comparable units could be anxiety provoking for some families, rather than perceived as open and transparent communication. The flip side postulate was the power and permission to advocate for your baby and for the needs of others, for example engagement with infection reduction QI giving explicit permission for families to challenge hand hygiene practices.

“You don’t really get to give the feedback about like patient safety”



Image 11: Opportunities for parent involvement with the NICU, including Parent advisor roles, Parent Buddies, and Veteran Parent Speakers

Timing of approaching parents for QI contributions was also felt to be key, “Maybe a year later, when you’re not so fresh at the time, after say “x” amount of time to get through the emotional response bit.” Development of relationships during the NICU journey, could be built upon with involvement in feedback, improvements, and projects after a respectful cool-down period after discharge. The

projects parents described being most enthused to develop or contribute to included effective discharge planning and standardisation of processes across regions and networks. **“After discharge isn’t life or death but preparing for what life looks like afterwards – there are lots of gaps there...”**. Standard processes and policies according to widely accepted best practice were felt to be areas which could benefit greatly from parent experience and their insights into several units during their often-complex journeys.

Image 12: Kiran and her beautiful family, some 4 years after the birth of her extremely preterm twins.



4.0 Discussion & Conclusions

Outcomes are improving worldwide for extremely preterm babies (EPBs), but the risks of death or significant long-term impairment remain significant. Data from NICUs in England certainly demonstrate improved survival over the last decade, but across the UK rates of survival and/or impairment vary up to 3-fold between units and networks. Canada has addressed similar variation within the CNN by way of the EPIQ improvement programme. Detailed analysis of 10 international datasets quantified the highest chance of survival for EPBs in Japan, the greatest difference seen at around 24 weeks gestation, where survival in Japan reached a remarkable 84% at that time.

Neonatal risk reduction is a highly cost-effective healthcare intervention with huge potential gains for both the constrained NHS and its' services, as well as infants and their families. Though expansive UK programmes have been rolled out to support improvements in maternal and neonatal care, translating this into tangible and sustained changes in outcomes remains complex. Draft guidance from BAPM, under review at the time of writing this report, is anticipated to propose that infants from 22 weeks gestation be considered for potential stabilisation, resuscitation and survival focussed intensive care. If we are to broaden the limits at which we offer active intensive care, now is the time to learn and benefit from the experience of countries already practising in this way. My observations suggest that innovations in kit and technology will rarely be the panacea; people and processes were master here. Social and organisational factors of an institution had a far greater impact on outcomes and improvement projects than policy in and of itself. Leadership seemed to be the gatekeeper to achieving our common goals of achieving excellent neonatal outcomes.

Practices & Culture

The Japanese model of care organisation is broadly comparable to the UK structure with “base and sub-base” hospitals delivering neonatal care. Japanese Perinatal centres (with NICUs) operate within Neonatal Mutual Cooperative Systems, akin to UK ODNs. Data from these centres contribute directly to the NRNJ research database with coverage currently estimated just over 2/3 of total eligible births nationwide. Whilst the mortality of infants not contributing to the national database is likely to be higher than those included, this does not detract from aspirational examples of best practice and exceptional outcomes for units such as OWC. Such units continue to represent important goals and exciting avenues for reviewing and improving our practices.

Clinical areas of care I found to be especially fascinating were those which may have greatest potential gains back home:

- Care in the first hours of life
- Neuroprotection and neuropromotion
- Infection control practices
- Gut health and breast milk

Areas of supporting practice and culture seemed key to effective care delivery. The utilisation of digital infrastructure in Japan was remarkable and there **are no specific barriers** preventing such transformation widely in UK units. The time these systems released for staff to care, train and perform key professional tasks was impressive. **Digital platforms supported detail, clarity and accuracy in care**, with the ability to review and learn from care episodes in near real time for the benefit of patients, families and teams. Financial constraints may feel significant in overwhelming in UK implementation but higher quality care will represent more cost effective care in any neonatal context.

Neonatal services in the UK should urgently lobby for comprehensive and accelerated digital transformation to support effective care of the EPB. This should be a key priority for the NHS in alignment with the Long Term Plan and could directly contribute to releasing staff time to champion and facilitate improvement work, also enhancing real-time data capture for important improvements in care.

The conformity of Japanese culture was obviously apparent and a clear contrast with our own. The climate of the teams was neither dogmatic, closed, static, nor with a fixed gradient of authority however. **Seniors were supportive, encouraging and motivated to “grow” their junior colleagues**, aspiring that their development to surpass themselves. Close working with nurses and AHPs was evident, and relationships were mutually respectful, this does not differ significantly from effective units in the UK and was also seen in Canada. Trainee doctors in Japan told me of the huge pride they took in their profession, the satisfaction of what they do “truly mattering to families” and their commonplace engagement with research and publications as “fulfilling the brain as well as the heart”. This seemed to parallel my experience of UK trainees to a lesser extent. Despite one week of leave per year as standard for Japanese trainees, their dedication and passion was obvious. There is a need for investment in trainees back home – supporting their professional development, nurturing a reciprocal dedication to the profession and role modelling for their own aspirations. The theme of **professional dedication and satisfaction was a recurrent theme; summarised as “Ikigai”**. “...this is a calling, we have an absolute responsibility to these babies and families.” Whilst this can’t be transplanted or borrowed from one culture to another, the concept of committed passionate leadership inspiring future generations of practitioner, is highly tangible.

Clinical foci from Japan

To expand on the key clinical domains, I consider a crucial area to be the **extended delivery room stabilisation** with early skin-to-skin care for all but the very smallest EPBs. This period of intense care, frequently delivered by the most senior clinicians possible was notable for both clinical content and potential impact on those delivering care. Non-resident consultants are commonplace out of hours in the UK and this would represent a challenge to routine and standard presence at such deliveries; these are often unanticipated. There may be further effects from highly experienced doctors performing hands on care in real time, rather than overseeing, sometimes managing remotely. **Comprehension of work as done with its attendant challenges, rather than work as imagined**, must surely contribute to empathy, support, and upkeep of practical clinical skills throughout career progression. Despite the common non-resident consultant model out-of-hours, we could positively sustain senior delivered care in the UK “in-hours” if desired - this happens already in some areas. The key difference is its standard, normal and expected execution in Japan.

The **clinical management during the designated “acute phase”** of 72 hours for EPBs is a second valuable target for improvement efforts. Many projects are focussing on this area already in the UK, but a minority will be combining an evidence-based improvement approach akin to EPIQ, with examples of care from high performing organisations and healthcare providers. The clinical teams in Japan have **a unified and, crucially, articulated goal** of avoiding IVH and brain injury, ensuring stability of infant physiology as far as possible. The gentle handling approach was straightforward, achievable, and demonstrably shared among the multi-professional team. This was one of the most adaptable elements of care I observed.

Reducing the risk of infection for babies on Japanese NICUs was not only a goal, common also to UK units, but was encouraged and reiterated verbally more than daily. Prompts were readily visible to emphasise the goal, and “failures” of the mission critiqued in a constructive, opportunistic manner. The ethos to **make the right thing the most straightforward** one I wholeheartedly encourage.

Support and infrastructure for encouraging maternal breast milk expression was in place both antenatally and in the immediate phase after birth. The **absolute normalisation of maternal milk for EPBs was everywhere**. I perceived most mothers seeing breast milk provision for their baby as a duty and responsibility, hence genuine buy-in to the drive for “zero formula”. The practice of unpasteurised milk sharing would be an unfamiliar and unlikely one in Western practice, but wider processes embedded to support maternal milk expression are entirely feasible in our hands. The investment in support staff, both financially and temporally, and wider training of all NICU clinical staff represent the key hurdles to greater progress in many UK units.

As in any comparative case, **not all practices observed in Japan were robustly evidence based** and some could appear illogical or unusual in the context of western practice. This study of policies, practices and people does not support blindly emulating Japanese practice in the hope that we happen upon a “magic recipe” for intact survival among babies born at threshold viability. I wholeheartedly support a critical, well-measured and locally tailored options appraisal for service improvement. **Translating rather than transplanting approaches is likely to deliver the marginal gains to progressively increment our key outcome measures**. Consistent collection, collation and reporting of key outcome measures will afford internal, network level and external benchmarking data for continuous QI. Effective responses to national benchmarking, such as the NNAP and MBRRACE reports, would be tremendously well supported by an open access neonatal community database of all improvement projects undertaken within NICU services. NICUs should support and encourage sharing of both effective and unsuccessful projects within their respective ODNs.

Canadian learning points

The **CNN high-quality database, free at the point of access, facilitates high quality research** where supported by a clear project proposal. This marries with the EPIQ programme, underpinned by the triad of 1) applying published high-quality evidence, 2) using hospital specific data to generate improvement targets, and 3) contributing to a national network for collaboration, sharing experience and expertise. Support for each hospital to explore its’ data in granular detail before developing specific and tailored priorities provides foundations for buy-in and ownership of local QI. A most valued aspect of the current iteration of EPIQ was **site-swap visits where practitioners targeting the same quality outcome visit one another’s institution**. The sharing is far deeper than displaying successes and minimising failures. The teams share and explore real life problems, lessons learned and key approaches to optimise interventions. It’s challenging to articulate the precise benefit of this adjunct but the teams best explained it as “being in it together” and seeing that others fail too – normalising the struggles of delivering excellence. A focus on optimising early care for EPBs should generate a menu of interventions and approaches in the UK, which can be shared through a comprehensive national database for exploring current and historical QI among preterm patients.

National CNN “Evaluation Groups” work on specified themes e.g. brain health, gut health, lung health, with open invitations to all HCPs at EPIQ participating centres. The groups’ publications offer a menu of interventions suitable for tailoring to specific issues identified in each hospital. Whilst there is surface similarity to UK NICE guidance, they are very different approaches to recommendations.

Where NICE guidelines are often implemented “as is” as best practice, the Canadian model allows for selecting those interventions as a “pic’n’mix” bundle which compliment the systems, populations and challenges of an individual unit. These were enhanced by training resident experts and champions in each Canadian NICU, often financially supported from academic routes. **The gap in UK models of funding requires a solution.** Neonatal services should review innovative options to establish, or embed, dedicated staff roles and time for neonatal QI considering the overall value likely to be added for the service. These roles should not be profession specific and should **attract additional targeted training in Improvement and Human Factors sciences.** To build upon the active improvement culture in the UK, such as the maternal and neonatal health safety collaborative, the neonatal community should develop and sustain specific relationships to support high quality QI in all NICUs. This could include a formal, long-term QI collaboration among all NICUs in the UK, similar to EPIQ Canada.

The greatest impediment to effective implementation of QI in the CNN was reported as lack of consistency in approach among senior clinicians. Teams found it challenging and disheartening to see seniors demonstrably at odds with respect to strategies for managing common and “uncomplicated” infant problems. I could relate to the sense of loss of direction, or failure to cohesively pull in one direction. A project should both employ compassionate, emotionally intelligent leadership among seniors, and be committed to valuing the team. These are the improvement interventions likely to be accepted, embraced and to effect change. This tied into the parent voices I heard throughout my fellowship.

Parental support and engagement

Parent isolation and lack of perceived support from peers was a clear and well vocalised focus for improvement efforts from Canada. QI efforts concerning peer volunteers on NICU had been extremely well received. Parents who had directly engaged with such projects valued their role tremendously and found satisfaction and pride in giving their time to others in a painful and challenging situation. Relationship building between teams and parents, engaging families within the NICU team rather than peripherally, seemed to be the cornerstone of achieving high quality infant outcomes and supporting future QI advocates. **Parent led, or at the least, meaningfully co-developed improvement projects were present in some Canadian units.** These projects became easy to identify among the myriad I explored due to the degree of parent appreciation, support, education and development they delivered. Remaining areas articulated for urgent QI were inter-hospital transport and retrieval, and consistency of care provision between regional hospitals. Whilst there are several practical barriers to providing a primary care team for any one baby and family, this is so highly prized among families, we must consider its merits and explore feasibility.

NICUs and UK ODNs should devise annual strategies for improvement including no more than 3 foci for change to reduce the impact of “change fatigue” on teams. These should be monitored and reviewed by the multi-professional team and led by a nominated Quality Lead for each service. Truly engaging parent experts within the improvement team can only come from a place of mutual respect and professional dedication. The timing to approach parents should be beyond the challenging transition home for most families to achieve the most fruitful outcomes. Developing supportive, nurturing and empowering relationships during the NICU journey could culminate in true co-leadership of QI with parents as partners.

References

- Campbell-Yeo, M. et al. (2015) 'Understanding kangaroo care and its benefits to preterm infants', *Pediatric Health, Medicine and Therapeutics*. doi: 10.2147/phmt.s51869.
- Celenza, J. F. et al. (2017) 'Family Involvement in Quality Improvement: From Bedside Advocate to System Advisor.', *Clinics in perinatology*. United States, 44(3), pp. 553–566. doi: 10.1016/j.clp.2017.05.008.
- Edstedt Bonamy, A. K. et al. (2019) 'Wide variation in severe neonatal morbidity among very preterm infants in European regions', *Archives of Disease in Childhood: Fetal and Neonatal Edition*. doi: <http://dx.doi.org/10.1136/archdischild-2017-313697>.
- Fowlie, P. W., Davis, P. G. and McGuire, W. (2010) 'Prophylactic intravenous indomethacin for preventing mortality and morbidity in preterm infants', *Cochrane Database of Systematic Reviews*. doi: 10.1002/14651858.cd000174.pub2.
- Hagen, I. H. et al. (2019) 'Parental satisfaction with neonatal intensive care units: a quantitative cross-sectional study', *BMC Health Services Research*, 19(1), p. 37. doi: 10.1186/s12913-018-3854-7.
- Helenius, K. et al. (2017) 'Survival in Very Preterm Infants: An International Comparison of 10 National Neonatal Networks', *Pediatrics*, 140(6), p. e20171264. doi: 10.1542/peds.2017-1264.
- Ikeda, T. et al. (2015) 'Changes in the perfusion waveform of the internal cerebral vein and intraventricular hemorrhage in the acute management of extremely low-birth-weight infants', *European Journal of Pediatrics*. doi: 10.1007/s00431-014-2396-1.
- Lee MBBS, S. K. et al. (2014) 'Association of a quality improvement program with neonatal outcomes in extremely preterm infants: a prospective cohort study', *CMAJ*, 186(13). Available at: www.cmaj.ca.
- Lee, S. K. et al. (2015) 'The evidence-based practice for improving quality method has greater impact on improvement of outcomes than dissemination of practice change guidelines and quality improvement training in neonatal intensive care units', *Paediatrics and Child Health (Canada)*.
- Nakanishi, H. et al. (2018) 'Trends in the neurodevelopmental outcomes among preterm infants from 2003-2012: a retrospective cohort study in Japan.', *Journal of perinatology : official journal of the California Perinatal Association*. United States, 38(7), pp. 917–928. doi: 10.1038/s41372-018-0061-7.
- Santhakumaran, S. et al. (2018) 'Survival of very preterm infants admitted to neonatal care in England 2008-2014: time trends and regional variation', *Archives of disease in childhood. Fetal and neonatal edition*. doi: 10.1136/archdischild-2017-312748.
- Unicef; Unicef Data, August 2019 <https://data.unicef.org/topic/child-survival/neonatal-mortality/>

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