Customer-Led Success Stories

The Glasgow Neonatal Unit

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A story of Customer-led success
The Glasgow Neonatal Unit

Follow this link for a summary of the framework explaining why customer-led success is so rare and the journey organisations go on to get there. Each story uses this framework so if you're not familiar with it or you want a reminder, it's worth reading this first to make sense of descriptions of terms like 'Burningness' and 'Moments of Belief' which are crucial

This is a story about a policy change in the Neonatal Unit of The Royal Hospital for Children in Glasgow. That might sound like a technicality but it's fundamental, a change in the shared beliefs that guided the way care was provided.

It has seen parents (the customers in this situation, at least the customer group old enough to speak) controversially taking the lead in the treatment and nursing of their premature and sick babies. Despite the perceived risks, this has had a profound positive effect on the lives of the babies, the families and the culture of nursing and care in the unit.

The burning need to do something different and two first moments of belief

The neonatal care system in the UK has, for many years, been associated with traumatic experiences. In cases where babies have ultimately had good outcomes, discharged in good health, the neonatal care experience has had long term adverse effects on the mental and physical health of both baby and parents, the latter sometimes suffering forms of PTSD.

Traditionally, neonatal units in the UK have been about high tech and specialist expertise. "The approach had been to get patients well quickly and then bring the families in," says Dr Neil Patel, Consultant Neonatologist at The Royal Hospital for Children in Glasgow. "Caring for sick babies tends to be highly technical, with a lot of procedure and equipment. Families get excluded unintentionally."

And at a time of such profound stress, in which some parents report feeling so emotionally bewildered that they are unable to ask even if they are allowed to touch their baby, a system that distances the parents is accidentally self-sustaining. With a baby's life at stake, what neonatal specialist would suggest that untrained parents do the caring? And what parent would say their baby would do better if they were helping to run things?

Despite the high standards of care, parents were expressing unhappiness. The feedback came through complaints and despite being taken very seriously, the organisation wasn't set up to understand what lay behind them and so truly address the issues that were causing the upset. Meanwhile, the individual neonatal staff who did try to be more inclusive of parents in their baby's care were seen as outliers, their actions seen as a voluntary addition to what mattered rather than being prioritised as a recognised component of care.

But in some developing countries, neonatal units don't have the luxury of the levels of staffing available in developed settings and greater parental involvement is needed. In his work training neonatal doctors and nurses in the Women's and Children's Hospital in Da Nang, Vietnam, Dr Patel saw first-hand the value of so-called Kangaroo Care rooms, where mothers, fathers and grandparents look after acutely premature babies around the clock, supervised by staff. But this only happens because there aren't enough staff or incubators, something that would constitute a crisis in the UK.

This was not a matter of mere passing interest. The work at Da Nang was generating data suggesting clear benefits for the babies cared for by their families – better weight gain, earlier discharge, increased success rates in breast milk feeding. This had a powerful effect on Dr Patel, one reinforced by a subsequent visit to the Mount Sinai Hospital Neonatal Unit in Toronto. The Canadian team members had been inspired by their own experiences working in another under-resourced unit in Tallinn, Estonia. What he witnessed in Toronto was what they had taken from their experience, something they called Family Integrated Care (FIC). This was a new neonatal approach that helps parents to be primary caregivers, working in partnership with the clinical team.

"One hour there completely changed my perception of involving families, and I saw that, in contrast to the costly technical upgrades we habitually pursued, here was a potential improvement that bore little cost or risk."

Dr Patel was convinced that changes in neonatal care born out of crisis in lower-resourced settings were presenting an opportunity to address needs in our own system, needs that would eventually become critical if left unchallenged.

An outside-in approach

The established approach to neonatal care has historically been rooted in control based on unspoken fear. Consultants and senior nurses operate in a command-and-control mode, making time-critical decisions and directing operations using their many years of experience. The fear was of losing any measure of control and listening to babies' parents might slow them down or expose them to dissenting points of view, creating conflict or raising problems they weren't trained to solve.

Dr Patel had seen a different way of doing things and he found himself increasingly determined to apply changes, originally made out of necessity in developing countries, to a unit at home that he simply wanted to be better. From burningness as pain to burningness as ambition. What he had not seen was that there was a hidden but equally burning desire in families (and colleagues as it turned out) to approach neonatal care with their babies in a more human way. Dr Patel invited his colleagues at the neonatal unit to a meeting he called the Family Communication Group, and then asked parents to join the meeting

in order to talk to staff about their communication needs. The meeting did not go to plan; instead of the parents talking about communications they described wanting to be taught how to care directly for their sick baby. They were asking for the FIC model of care without ever knowing it existed.

This was a shock to the clinical staff, and it lit a touchpaper. Hearing the families directly express their wish to be carers inspired nurses and consultants to take control of their unit and to do things differently. This was despite a historically restrictive and hierarchal culture in the NHS. It felt risky. They weren't diverging because of a directive from senior management, but because of a challenge from their 'customers', the families that wanted the unit to change; the team decided they didn't need permission, they wanted to do it their way and were prepared to take responsibility for the changes they made.

Bold new outside-in beliefs

Still taken by the looks of horror on many faces when he'd told his colleagues he was inviting parents into their meeting, Dr Patel was surprised and relieved to afterwards receive feedback from a senior colleague that it had been one of the most inspirational meetings he'd ever attended. This was a crucial first moment of real belief for the team.

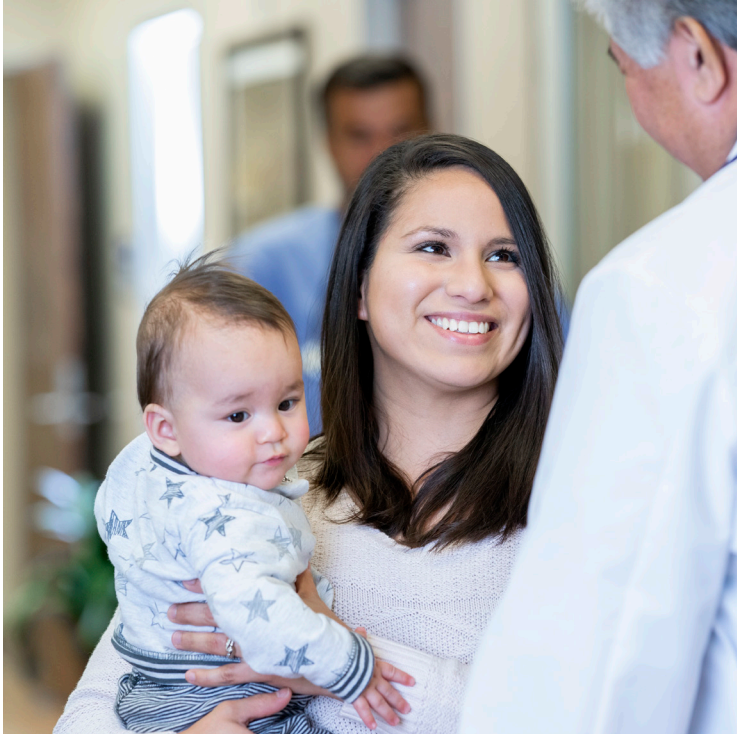
> "They gave us permission to be human on a Monday morning"

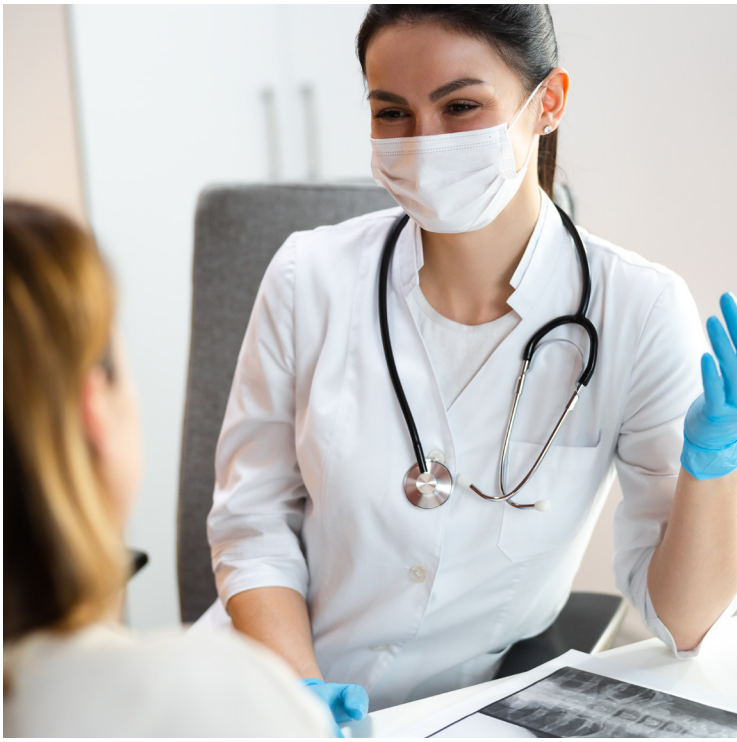
The more they listened to babies' parents, the more they realised that huge inside-out assumptions had been made about what families really wanted.

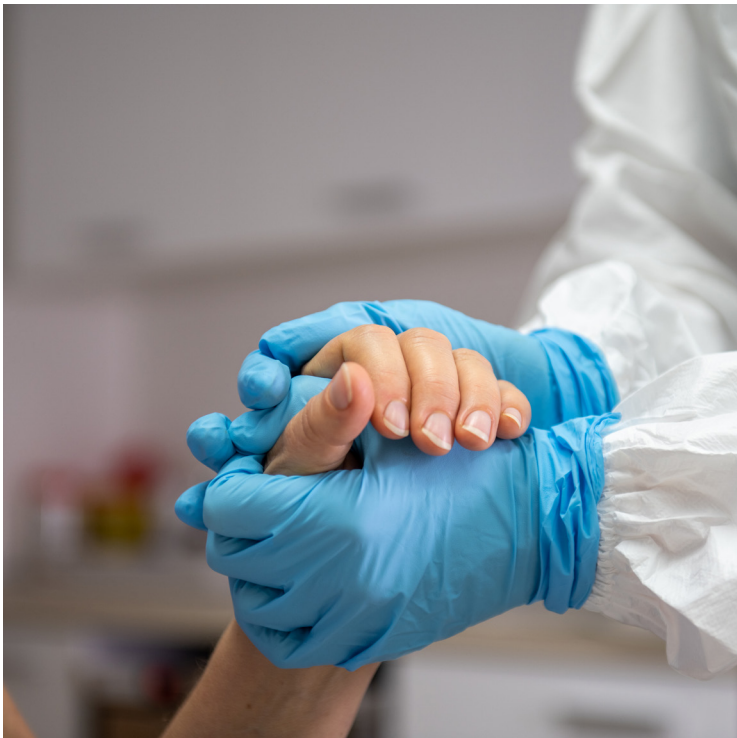
They thought families wanting to be present on ward rounds would throw up impossible obstacles around privacy and confidentiality, but the families said they didn't care about other parents overhearing clinical details and trusted the team not to say the wrong thing.

They presumed parents expected them to know everything about their baby, and as a result would sometimes make excuses to take time to read up clinical notes, keeping parents waiting. But parents reassured the team that they would prefer to be asked about their baby in order to help clinical staff get up to speed. "They gave us permission to be human on a Monday morning," notes Dr Patel.

Another false belief was that parents didn't need or want to know all the details. "We often find ourselves







using generalisations like she's had a settled night, but in the conversations we have with parents they've told us they want specifics, she slept from 2-5am, then had a 40ml feed, then vomited twice… her next feed is due at… In retrospect it's completely understandable, but we had a misplaced, slightly paternalistic view that if we didn't go into detail it would be better for them."

In Glasgow, the parents now expected the unit to begin again with not just a blank sheet but a totally open mind. They needed staff to put aside assumptions and place their views front and centre. The team responded by drawing up a whole new policy towards neonatal care from the ground up, starting with the normalisation of Kangaroo Care, the practice of skin-to-skin contact between infant and parent. This saw improved cardiorespiratory and temperature stability, sleep organisation and duration, neurodevelopmental outcomes, breastfeeding and modulation of pain responses. Mothers began to show enhanced attachment behaviours and to describe an increased sense of their role as a mother.

These successes led to a wave of more nuanced moments of belief which further shifted the emphasis of neonatal care at Glasgow from the inside-out expert tech approach to an outside-in trusting and supportive human practice:

- Whiteboards were installed at the foot of each bed where staff and parents could leave messages for each other: words of thanks, support, as well as shared communication about care. Colleagues, especially on nightshifts, wrote updates and messages of encouragement, including translations for non-English speaking families. One parent left a message saying, "thank you for being a voice for my baby."

- A video messaging system was introduced at the suggestion of a father who asked if he could be sent short videos of his son when he could not be present in the unit. Staff could now create video messages, often during the night, and send these securely to parents, who feel reassured receiving them. The bond with staff was strengthened and mothers reported that receiving a video of their baby from the ward reduced their anxiety, aided their sleep and helped them express breast milk.

- A biometric fingerprint entry system was brought in after families expressed the tension caused by having to wait to be let into the unit. They associated a long delay at the door with a crisis on the ward that their own baby might be the subject of. The unit benefitted from no longer having to have a member of staff stop work to open the door an estimated 150 times a day.

The cumulative impact of these small customer-led changes established the unit's principle of committing to FIC without the advance promise of the measurable results and control delivered by technical care. This philosophy of informed bravery based on customer benefit is at the heart of a new culture which has seen the normalisation of the idea that the unit meets the needs of the baby and the baby's family, with positive clinical outcomes and other immeasurable gains the result.

Sustaining the new belief system

What made the new way of doing things at Glasgow move from experimental to systematic was listening to the families. Doing this is what keeps the team connected to parents coming into the unit. It ensures, in a tangible way, that the team pay continual attention to their new outside-in approach and keep it fresh and fit for purpose. It deepens the foundations of the new beliefs so that they are strongly held and fully shared. This is why the prevailing, unambiguous belief has become that this level of family-centric innovation is the way things are now done around here.

As well as daily meetings, the unit now holds Helping Us Grow (HUG) group meetings every four to six weeks. These are always packed. New families come in with fresh ideas meaning that the work moves on. Dr Patel facilitates this by keeping the agenda of HUG meetings loose. "The conversation goes where it needs to go." All colleagues are surveyed, without exception. "We talk with those who aren't coming to meetings and get their opinion, so that this is not a new policy being enforced but something we do together by reaching a consensus view."

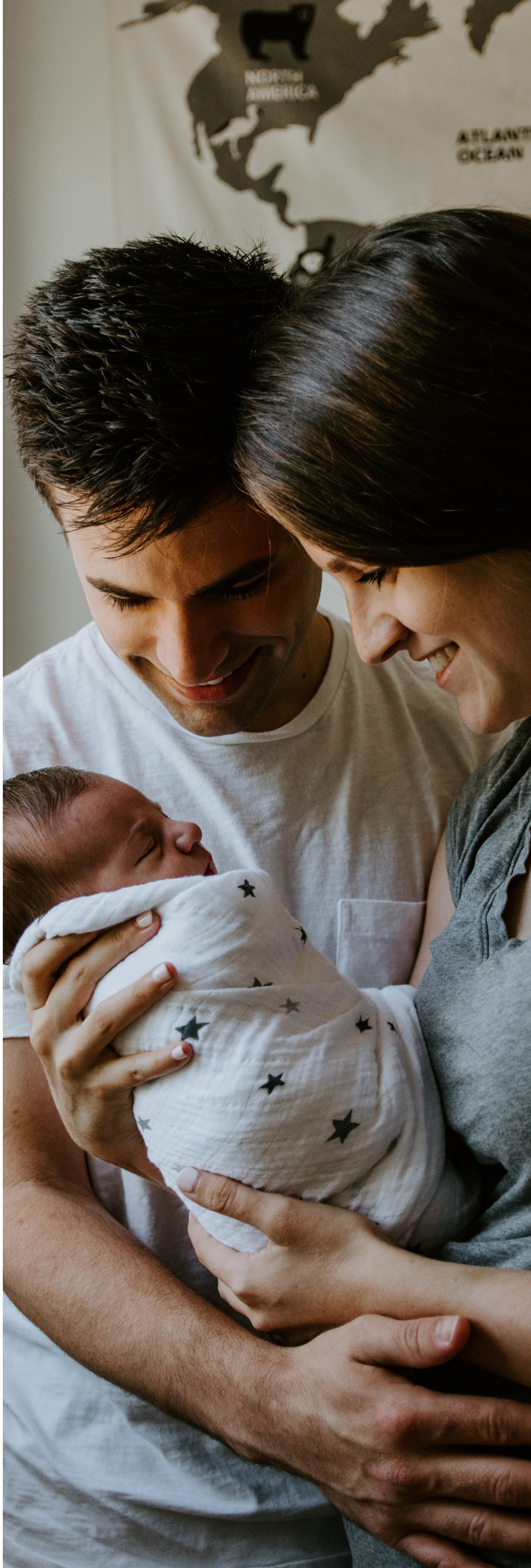
Staff and parents have formed subgroups to lead different strands of improvement in the unit, coordinating their work using WhatsApp to communicate rapidly. Each subgroup is encouraged to think differently to meet challenges and find improvements in FIC. A support group, Peer to Peer, runs family awareness sessions. There are joint teaching sessions for staff and families, and special days to promote staff education, like International Kangaroo Care Day. One group thinks creatively about the ward environment, resulting in improvements like the introduction of reclining chairs at each cot-side for parents to perform skin-to-skin care and breast milk feeding.

In the early stages of FIC at Glasgow, the unit

assumed that all parents would want to be involved in their baby's care. But they are learning, by listening to them, that each parent is different – that some want to be involved from day one whereas others need time and encouragement to feel confident. They also learned that things can change day-to-day. The key is supporting each family as and when they are ready and challenging their own commitment to family involvement so that they offer something far more bespoke and sensitive than a one-size-fits-all FIC policy, which could be potentially harmful.

The unit continues to examine its own assumptions and ideas, with the ambition of maintaining a continual flow of moments of belief, actions that reinforce their customer-led approach. For example the decision was made recently not to follow the example of other hospitals where nursing staff have been appointed as paid FIC leads, because the aim at Glasgow is to have parent-led patient care supported by all staff doing what they can. Their own model is one in which parents and staff are committed to doing the extra work between them with no emphasis or burden placed on any one individual, and where the unit delivers this as part of its normal care, not as an add-on at extra cost.

Their belief is that their outside-in ethos will be best served by not accepting funding for, or in any way formalising, FIC roles at Glasgow. They are being boldest by rejecting the opportunity to formalise their model.



Outcome

Does it work? According to UNICEF, it does. UNICEF's Baby Friendly Accreditation external assessors gave Glasgow's Neonatal Unit their sought-after Level 3 accreditation in 2018, Glasgow becoming one of the first tertiary surgical referral centres to achieve this level of recognition in what UNICEF describes as, "excellence in the care of mothers and babies."

Results in the most important field of clinical benefit to the baby have been impressive. Increased breast milk feeding leads to associated benefits of improved immunity, improved neurodevelopment, reduced infection, reduced necrotising enterocolitis (a severe and potentially devastating gut-related complication of prematurity) and reduced lung disease in preterm infants. There have also been improvements in rates of weight gain, earlier discharges from hospital and in increased holding and Kangaroo Care (this FICare approach bringing benefits proven in Canadian studies).

Parents of sick babies have benefitted from reduced stress, earlier discharge and improved confidence at discharge, and improved long-term psychological outcomes, including reduced PTSD symptoms.
The benefits for the NHS are significant, with the potential for large numbers of earlier discharges and fewer re-admissions. The customer-led approach to neonatal care at Glasgow supports the NHS' long-term social strategy for self-management and person-centred care and supports Scotland's Realistic Medicine policy of a person-centred approach to improving quality and safety of care. There are fewer complaints and improved safety of care because parents speak up to prevent errors and because of the unit's approach spreading to other paediatric and non-paediatric disciplines. The positive publicity and public engagement with FIC has led to Glasgow's unit benefitting from increased charitable support.

More than a quarter of a century ago, Kangaroo Care for low-birthweight infants was introduced in a neonatal unit in Bogota, Colombia, in direct response to a crisis of overcrowded nurseries, with too few incubators and high rates of neonatal infection and mortality. In the UK, not long ago, nurses who tried to bring Kangaroo Care into their personal practice were viewed with suspicion. Now, those nurses are seen not as outliers but as early trailblazers for what has become the norm. Dr Neil Patel wants it to soon be the case that families can't believe how neonatal care used to be. "If I had one simple message from our work," he says, "it would be to listen to the families and staff and help them lead the change."

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