



**Locked out: the impact of
COVID-19 on neonatal care**

Bliss
for babies born
premature or sick

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Methods

This report is based on a survey of parents whose baby, or babies, had spent time in neonatal care in the UK between March 2020 and February 2021. 510 parents responded to the survey, 460 respondents identified themselves as the mother of a baby, or babies, who spent time in neonatal care, 48 identified themselves as the father of a baby, or babies, who spent time in neonatal care and 2 identified themselves as the legal guardian, but not the birth parent, of a baby who received neonatal care. 58 responses were from a parent of twins or multiples. Respondents lived in England (432), Scotland (44), Wales (30) and Northern Ireland (4). The majority of our respondents' babies had gone home from the unit (434), 75 were still receiving neonatal care when their parents filled in the survey and sadly, 11 had died while receiving neonatal care.

To understand how NHS England guidance *Supporting pregnant women using maternity services during the coronavirus pandemic: Actions for NHS Providers* has been implemented, and the barriers that Trusts have faced in facilitating parental presence on neonatal units, we conducted a survey of 161 NHS Trusts in England. The survey was conducted between 26 February 2021 and 26 March 2021. We received 70 responses (a response rate of 43 per cent) to the survey from 15 Neonatal Intensive Care Units (NICU), 35 Local Neonatal Units (LNU), 16 Special Care Baby Units (SCBU) and 4 Surgical NICUs.

Throughout this report, we use the term 'parent' to mean all parents, carers and legal guardians of a baby born premature or sick who is receiving neonatal care and their partners or support persons.

About Bliss

Bliss was founded in 1979 by a group of concerned parents who discovered that no hospital had all the equipment or the trained staff it needed to safely care for premature and sick babies.

Determined to do something, these volunteers formed a charity to give vulnerable babies the care they deserve. More than 40 years later Bliss has grown into the UK's leading charity for babies born premature or sick. Bliss champions the right for every baby born premature or sick to receive the best care.

We achieve this by empowering families, influencing policy and practice, and enabling life-changing research.

Summary

Typically, neonatal units facilitate unrestricted access for both parents, so that they can care for their baby whenever they need to. Neonatal units in the UK strive to provide Family Centred Care environments which support and empower parents to be partners in their baby's caregiving and decision making. From March 2020, neonatal units across the UK began introducing restrictions to parental access in response to the growing pressures of COVID-19 and to comply with nationally mandated hospital-wide visiting restrictions. This report shows that these changes have caused harm to some babies and their parents.

We have gathered evidence from parents whose babies received neonatal care during the pandemic to hear about the impact of the restrictions imposed on neonatal units. We have also surveyed NHS Trusts in England about the barriers they are experiencing when it comes to facilitating parental presence on neonatal units.

We found that:

- In March 2021, neonatal units were still routinely restricting parents' ability to be with their baby. Just 27 per cent of units that we spoke to were facilitating full access for both parents ensuring they could be with their baby, together, whenever they wanted. Nearly half (46 per cent) did not routinely offer parents any time to be with their baby together.
- 61 per cent of parents who responded to our survey said that restrictions on the unit had affected how much they could be with their baby or babies. Parents were more likely to report feeling that restrictions had impacted their ability to be with their baby if: they spent more than 4 weeks on a unit; their units' policy did not enable both parents to be there together; a limit was imposed on their time with their baby.
- Parents particularly highlighted to us that not parenting together meant that they were unable to be supported by their partner or provide support to their partner in return and that time-limits and not being able to come and go freely made them feel like they weren't being treated like a parent.
- The majority of Trusts that responded to our survey said that parents were either unable to attend ward rounds at their unit, or that only one parent could attend. This has led to parents feeling unsupported while receiving bad news and feeling overwhelming responsibility to communicate complex medical information accurately to the baby's other parent – one parent receiving information second cannot ask questions/be as involved in care and decision making.
- 41 per cent of the parents we spoke to said that going through a neonatal admission during the pandemic restrictions affected their ability to bond with their baby at some point during their journey.
- Parents were more likely to feel that bonding was affected if their baby received care on a unit where their access to their baby was time-limited or if they were still on the unit when they completed the survey.
- The majority of neonatal units that we spoke to (76 per cent) said that parents must wear PPE at their baby's cot-side on their unit, and almost half (47 per cent) were unable to allow parents to take off PPE even when they held their baby.
- Parents were concerned that wearing PPE was affecting bonding, their baby's development and breastfeeding. In particular, there was concern over wearing PPE (incl. apron and gloves) when breastfeeding or having skin-to-skin.
- The impact on parents is clear to see with 69 per cent of the parents we spoke to saying their mental health has got worse as a result of their neonatal experience and 56 per cent said the mental health of their partner and wider family has been affected.
- Parents were more likely to say that their mental health had been affected if their baby's stay was more than 4 weeks, if they were unable to care for their baby at the same time as their partner or if there was a time-limit imposed on the time they could care for their baby.

We're recommending that

- NHS England and the Scotland, Wales and Northern Ireland Governments must each publish a National Neonatal Roadmap setting out how neonatal units will return to usual family access.
- All nations must provide clear guidance for Trusts and Health Boards to ensure neonatal services are facilitating one metre plus social distancing rules when other mitigations, including face coverings and negative COVID-19 tests, are being utilised.
- The Departments of Health in both Wales and Northern Ireland must immediately update national guidance to ensure that there is no blanket national policy to prevent parents caring for their baby together on neonatal units.
- In line with existing national guidance, Trusts and Health Boards should never consider parents as visitors to a neonatal unit and should therefore not apply wider hospital visiting guidance to parents of babies receiving neonatal care.
- Neonatal units must maximise opportunities for involvement in care and decision making for parents and family members, particularly where full-unrestricted access is not in place.
- Governments and NHS bodies must develop clear action plans to mitigate the impact of further lockdowns or future pandemics on neonatal services. Plans should be developed in partnership with neonatal networks, neonatal units and service users. They should take a family centred approach, prioritising parent's access to their baby and involvement in their care.

Introduction

For more than a year, nearly every area of life has been affected or modified in some way to manage the transmission, and to minimise the impact, of COVID-19. Life within a neonatal unit has been no exception.

More than 100,000 babies born prematurely (before 37 weeks of pregnancy), or full term but sick across the UK every year receive care in a specialist neonatal unit shortly after they are born. Many of these babies will remain in hospital for a few days, while others will receive life-saving care for weeks or months before they are ready to go home. Very sadly, some babies will never go home at all.

Typically, neonatal units facilitate both parents to have unrestricted access to their baby. Wider family members or key support people – such as siblings, grandparents and friends – are usually also able to visit, although such visiting may be restricted, particularly for those babies requiring critical care. Neonatal units in the UK strive to provide Family Centred Care environments which support and empower parents to be partners in their baby's caregiving and decision making. From March 2020, neonatal units across the UK began introducing restrictions to parental access, and paused visits from wider family members entirely, in response to the growing pressures of COVID-19 and to comply with nationally mandated hospital-wide visiting restrictions^{i ii iii}. As this report shows, these changes have caused harm to babies and parents.

The early months of the pandemic were characterised by regularly changing clinical guidance and wide variation in parent access policies, including the emergence of extremely restrictive nominated carer policies, meaning only the same parent or carer could attend the unit, which left some parents and carers unable to see their baby for weeks. Staffing levels were also significantly affected in some areas due to increased absences related to sickness, self-isolation and shielding, as well as redeployment of staff to different services.

Bliss issued the first version of our *Position Statement on Parental Access and Involvement* in April 2020, outlining the importance of parental partnership in neonatal care and decision-making for ensuring babies and their families have the very best outcomes. More than a year on, this report shows that there is still persistent variation in unit policies, with many families only having their first opportunity to see and care for their baby together as a whole family unit when they go home. Our findings also highlight the devastating impact on the emotional well-being of many families who have cared for their babies through these restrictions.

While modifications to service delivery have been necessary to maintain safety for babies, families and staff there has been a significant detrimental impact on parent and family experiences of neonatal care, and it is currently unknown if there will be a longer-term impact on babies who received care during this extraordinary period. As the UK moves rapidly towards opening up from successive lockdowns^{iv} it is time for neonatal services to begin moving rapidly towards reinstating pre-COVID-19 parent access and family involvement policies. The findings of this report should not only shape practice over the coming weeks and months, but be used to inform future response to similar events to prevent avoidable harm.

What does the evidence show?

Evidence¹ supports the need for parents to be involved in their baby's neonatal care, as parental involvement in their baby's care is proven to be best for babies' developmental outcomes. Long periods of direct care lead to increased weight-gain and improved breastfeeding rates, and skin-to-skin care has been linked to better infant reflexes at term and better gross motor development at 4-5 years.^{vi vii} Further, parental involvement in care is critical for bonding and forming secure attachment. Parents who are supported to be with their baby for prolonged periods of time report increased parental confidence, reduced stress and anxiety scores.^{viii} Providing direct, hands on care allows parents to feel like parents - which may be key for their own perceptions of attachment to their baby - and physical and emotional closeness is crucial for forming strong parent-infant bonds.^{ixx}

As with all other areas relating to COVID-19, in March 2020 when restrictions began there was no evidence about how susceptible to the virus babies would be and how likely transmission was to occur during birth or in neonatal settings. Throughout the last year, evidence has been gathered both on the likelihood of transmission and the impact of restrictions placed on neonatal units.

COVID-19 is uncommon in babies admitted to neonatal care in the UK. Research concluded that babies were unlikely to be admitted to a neonatal unit following birth to a mother with perinatal COVID-19 and that, while transmission of the virus from mother to baby during pregnancy or birth could not be ruled out, this is extremely rare^{xi}.

Babies born to mothers with COVID-19 are more likely to be born prematurely and needing neonatal care. Research has not linked the increased risk of premature birth to clinically significant effects of the virus on the baby. Instead, higher preterm births in mothers with the virus is linked to the need for early induction if the mother's health deteriorates due to COVID-19. Infection in pregnant mothers is not associated with stillbirth, early neonatal death or babies who are small for gestational age^{xii}.

Evidence overwhelmingly supports avoiding the separation of babies from their parents. While there is some evidence of hospital acquired infection within the neonatal unit, this is rare, and generally of little clinical significance for the baby. Further research is required to understand the effects of hospital visiting restrictions on the spread of this and other highly transmissible viruses in hospital settings^{xiii}. However, there is evidence that the impact of reduced skin-to-skin and kangaroo care is substantial, especially when considered globally where these interventions can be lifesaving^{xiv}.

Evidence published over the last year about COVID-19 restrictions on neonatal units in the UK has shown that changes in parental access policies are widespread, but approaches to implementation have been highly variable. Staff report concerns about the impact of these changes including that parents were not able to spend as much time with their baby, parents lacked support from family and other parents, reduced communication between parents and their baby's clinical team, reduction in breastfeeding rates and concerns over the developmental impact on babies of parents wearing masks^{xv}.

Studies suggest parents feel that bonding has been impacted and that their ability to participate in their baby's daily care has been curtailed^{xvi}. Evidence also suggests that access restrictions that stop a mother being with her baby on the neonatal unit can lead to a decline in breastmilk feeding rates^{xvii}. Since June 2020, there has been a requirement to wear face-coverings while in hospital. Existing evidence indicates that this may have an effect on development, as well as impacting the effectiveness of communication and joint decision making^{xviii}.

¹The evidence highlighting the positive impact of family involvement in care was first published in Bliss (2020) Bliss Statement: COVID-19 and parental involvement on neonatal units

National Guidance for neonatal units

Bliss published a Position Statement on Parental Access and Involvement on 8 April 2020 which has been updated regularly over the past year. Since April 2020 we have called for services to enable both parents to have access to their baby, preferably together, without a time-limit. We have also highlighted that it is essential for parents of critically ill or palliative care babies to be able to have unrestricted access regardless of unit policy and COVID-19 status. Later versions of the position statement also include recommendations on removing face coverings at the cot-side.

National bodies also published guidance throughout the pandemic including the British Association of Perinatal Medicine^{xix}, RCOG^{xx}, Public Health England's Infection Prevention and Control Guidelines^{xxi} as well as guidance relating to vaccine roll-out from early 2021.

The four nations of the UK have taken different approaches to providing guidance for neonatal units. Northern Ireland, Wales and Scotland issued guidance to Health Boards and services in the early stages of the pandemic. Northern Ireland and Wales^{xxii} have maintained restrictive policies throughout, only allowing one parent to be present at a time. Northern Ireland's updated guidance^{xxiii} currently includes an easing of restrictions on neonatal units - supporting both parents to be present on the unit together.

The Scottish Government has regularly updated their guidance, which provides neonatal settings with minimum standards for visiting during the pandemic under each protection level (zero to four). This guidance has consistently sought to treat parents as partners in care, who should not be treated as visitors to a neonatal setting, and currently stipulates that even in the highest protection level units should support parents to be on the unit together (subject to local risk assessments and physical distancing). New guidance from the Scottish Government, updated in April 2021, now also indicates that siblings should be able to visit neonatal units^{xxiv}.

In England, national guidance took a lot longer to be developed. Guidance was issued for the first time in September 2020 for Maternity services in England, but did not include neonatal care. NHS England did not publish guidance^{xxv} including neonatal care until December 2020. This guidance clearly stated that parents should never be considered visitors as they are partners in their baby's care. It set out three actions for units to take which are risk assessments; changes to the configuration of space on the unit; and COVID-19 testing for parents.

There has been varied practice between different perinatal services within the same hospital, as well as between regions and nations. In England in particular, three tests were set but with no mechanism to record compliance or outcome, which is what our findings will address.

In response to parental separation, there has been increasing use of video technology platforms over the past year. While this technology has allowed parents to be kept in touch with their baby, and has supported outpatient appointments and ward round communications, it is important to note that this may have some benefits for parents who are not able to access the unit, but it is in no way a replacement for parents' physical presence with their baby, and also provides no benefits to babies receiving neonatal care.

Restrictions and their impact on families

Bliss' survey of NHS Trusts in England reveals a high level of variation in practice relating to parent access to neonatal units, that remained endemic in March 2021. This can be seen as both a reflection of the different contexts that each unit operates in but also as a consequence of the vacuum left by a lack of national direction from NHS England and national government from the start of the pandemic, up until December 2020, about how to facilitate parental presence on neonatal units, and the importance of doing so.

Restrictions on parent access to neonatal units

The majority of units who responded to our survey were supporting 24-hour access for at least one parent by March 2021, with 91 per cent providing at least one parent 24-hour access to their baby. **However, only 27 per cent of units that we spoke to were facilitating full access for both parents ensuring they could be with their baby, together, whenever they wanted.** Where both parents had 24-hour access to their baby, this was often just one parent at a time.

For neonatal units not providing full and unrestricted access to both parents, a variety of different policies were in place. **Nearly half (46 per cent) did not routinely offer parents any time to be with their baby together,** while 26 per cent gave parents the option to book a slot in which both parents could be at their baby's cot-side together for a short period. Around ten per cent of the units that we spoke to had limited the amount of time in which both parents could be with their baby. Other restrictions imposed that could act as a barrier to one or both parents seeing their baby for as long as they would have liked included one nominated parent per 24-hours (or other specified time period) and not being able to return to the unit that day once you have left.

Consequently, the experience of parents on neonatal units, and their ability to be involved in their baby's care, has been impacted considerably by restrictions to parental presence on units throughout the COVID-19 pandemic. Parents find that they are unable to be with their baby as much as they need to be and some parents - usually fathers or the non-birthing partner - are unable to spend time with or be involved in their baby's care at all. The implications of this on family bonding and mental health are clear, and the isolation that parents have felt at this time has been near universal.

61 per cent of parents who responded to our survey said that restrictions on the unit had affected how much they could be with their baby or babies. Parents were more likely to feel that restrictions had affected how much they could be with their baby "to a great extent" if they spent more than four weeks on the unit. They were also more likely to feel that there were times when they wanted to be with their baby but couldn't if their baby had received care on a unit that did not support parents to be at the cot-side together, or a unit that imposed time-limits on how much they could be with their baby.

The impact of not parenting together was a key theme in these responses and impacted parents in a multitude of ways. Parents highlighted that attending the unit alone meant that during one of the most challenging times in their lives they had no support from their partner, and their partner had no support from them.

"[I felt] depressed and upset as we didn't know if our twin 2 would survive. She had a major heart defect and when in intensive care on a ventilator I had absolutely no support. I wasn't allowed my partner in with me which was absolutely horrific [as] we didn't know if she would make it. It's had a very traumatic effect for myself and my partner." **(Mother of twins born in June 2020)**

"It's made the hardest time of my life harder. It's made me feel more distant from my babies and unable to support my husband (or be supported by him) at times when we have needed each other." **(Mother of twins born in October 2020)**

"We understood that [the restrictions] had to be in place as we are in a global pandemic. However, we were going through the toughest time and we are a partnership who needed to support each other." **(Mother of a baby born in October 2020)**

Parents told us that the restrictions in place on units made them feel like they weren't being treated like a parent and like their rights as a parent were being taken away. This was expressed particularly strongly by parents who had to book in time to be on the unit and could not come and go freely as they would under usual practice.

"[I felt] Like I wasn't her mum. Like someone else was raising my baby. Like me and her dad weren't important enough to be there. All of the 'firsts' I should have been able to do with my baby were taken away from me." **(Mother of a baby born in April 2020)**

"[The restrictions] made me feel as though my baby wasn't really mine at that stage, as though parenthood was on hold and waiting to start. I could not see my husband be a father to our son, and I felt as though I had to ask permission to hold our son." **(Mother of a baby born in April 2020)**

"[I felt] Upset, anxious and traumatised. I didn't feel like my baby knew who I was." **(Mother of a baby born in July 2020)**

"I feel deprived of my rights as a mother." **(Mother of a baby born in August 2020)**

Units have not been able to accommodate wider visiting to neonatal units including other children. This presents issues for parents who have older children at home. Parents told us that this can have a serious impact on their other children. It has also made the practicalities of both parents spending time on the unit difficult and acts as a barrier to one parent attending the unit.

"As much as we were able to be involved the inability for siblings to meet made it very tough on the family especially as I was in hospital for two weeks and a single parent, and it made my children incredibly anxious as they are older and thought their brother was going to die and that's why they weren't allowed to see them." **(Mother of a baby born before March 2020)**

"Siblings not being allowed to visit was tough as my 3-year-old didn't meet his brother until he was discharged at 5 weeks old. It also meant that neither parent could visit as much as we would have liked." **(Mother of a baby born in August 2020)**

"My daughter's siblings could not understand what was happening and why they could not visit, or why I kept going away (the unit was not geographically close). The children became quite anxious about how long I would be gone for etc." **(Mother of a baby born in October 2020)**

"[Our] mental health was severely affected due to the guilt of not being with our other children and them not being able to visit due to Covid restrictions. Siblings were upset and worried due to not knowing or being able to be involved." **(Mother of twins born in October 2020)**

"Lack of access to childcare for elder sibling meant that before mum was discharged I went a week without seeing baby as siblings could not enter unit. This meant I missed a lot of early bonding." **(Father of a baby born in April 2020)**

Parents whose partner cannot be on the unit with them, and single parents, may be left without any support on units where access is restricted to a strict definition of parent. Enabling parents to nominate a support person to be treated as a parent/carer during this difficult time would provide fairer access to support. A mother of twins whose partner had no choice but to return to work told us:

“Not allowing grandparents etc. in made it very difficult to make sure both babies were getting contact when my husband had to go back to work and the babies were in different rooms. I had to try and split my time between both babies; whereas if a grandparent had been there they could’ve held the other baby and I’d have felt less guilty.” (Mother of twins born in January 2021)

Communication and decision making

For parents to be fully involved in their baby’s care and decision making they need to be present and able to participate at ward rounds to hear about their baby’s health and care, contribute their views, and ask questions. Pandemic restrictions have led to parents being less able to be involved in these crucial discussions. While 84 per cent of the units we spoke to said that at least one parent could attend ward rounds, almost half (44 per cent) of those parents had to attend alone, without the support or involvement of the baby’s other parent or a support person. There is also a small but significant minority of parents (16 per cent) shut out of these discussions entirely.

Speaking to clinicians without a partner left parents unsupported when receiving bad news where policies prevented parents from being on the unit together. Many respondents expressed feeling an overwhelming pressure to relay complex medical information accurately to their partner and to be able to answer their questions when they had been the sole recipient of information about their baby’s condition. This also meant that they had to be the one to impart bad news to the parent that couldn’t be on the unit when there was something wrong. The parent receiving information second hand was unable to ask questions of their baby’s medical team and prevented from being actively involved in decision making. For both parents, they were forced to digest sometimes life-changing information alone without the support of their partner or support person.

“Having to talk to consultants alone with[out] the support of a partner when discussing whether your baby was going to live. Having to stand there ALONE as they resuscitated your baby without your husband by your side. This was detrimental to my breast milk supply and my mental health as this went on for 119 long days.” (Mother of a baby born in April 2020)

“[I felt] lonely as I felt I had to deal with it all by myself, the weight of responsibility to understand and convey information correctly, sad that Dad was missing early moments, exhausted from no break” (Mother of a baby born in March 2020)

“[It made me feel] more anxious and confused as I didn’t understand the medical terms as much as my partner and I wasn’t able to explain properly what was being said to me to my partner” (Mum of a baby born August 2020)

“We felt isolated, we needed each other, and it caused myself to feel scared anytime a doctor came in case they told me something bad when I was alone.” (Mother of a baby born in December 2020)

Bonding under access restrictions

Parents also told us that COVID-19 restrictions affected their perception of bonding. **41 per cent of the parents we spoke to said that going through a neonatal admission during the pandemic restrictions affected their ability to bond with their baby at some point during their journey.**

Parents who filled in the survey while they were still on the unit (n=74), were much more likely to say that they felt that bonding had been affected (57 per cent) than those whose baby had been discharged (40 per cent). This was reflected in the comments around this question with some parents telling us that they felt that bonding had been affected while their baby was receiving neonatal care. This did not always continue once they were home though, and some parents told us that they did not think that there had been any long-lasting impact on their bond with their baby. This may be of some comfort to parents whose baby is currently receiving neonatal care.

"I felt useless to my baby and didn't bond with him until home. I also felt alone and that no one in my family understood how I felt." (Mother of a baby born in March 2020)

Parents were more likely to feel that bonding had been affected if they had their time with their baby limited by access restrictions. **30 per cent of parents who had no limit imposed on their time with their baby said that they felt bonding had been affected, in comparison to 51 per cent of those who had been on a unit with a time-limited access policy.**

While we know that the majority of units are no longer imposing a definitive time-limit on both parents, a one parent per cot policy does effectively limit one or both parents' ability to be with their baby as much as they would like. This is seen in the comments we received about bonding and other topics where there was a high level of concern about the experiences of parents who couldn't be on the unit very much. Some parents who spent the majority of the time on the unit mentioned that their partners struggled to bond with their baby as a direct result of spending less time on the unit.

"Not for me, but my husband has struggled to bond with our baby at the start. He didn't get to be at the birth or meet her until she was five days old. That was the only time he was able to see her until she came home." (Mother of a baby born in March 2020)

"Dad wasn't able to spend much time with our twins before they came home. He was only able to visit once. He felt this impacted his bond with the boys greatly." (Mother of twins born in August 2020)

"[My partner] became severely depressed whilst being kept from them. He spent 9 weeks away, with his last conversation with their consultant being how they weren't expecting our smallest to make it. That tormented him for the entire time before he was allowed back. When he finally was [able to go on the unit] they were four times their birth size and totally different babies." (Mother of twins born in March 2020)

"[I felt] alone. I only saw our baby together once for his first bath and not again until discharge. I also felt that because we could only be one at a time, my wife and I rarely spoke to each other during the day while we were there." (Father of a baby born in July 2020)

Many parents told us that they felt like they struggled to bond as a family, having never, or only briefly, spent time together with their baby. They did not get an opportunity to learn how to parent their baby together and they found spending time on the unit separately meant that one parent often missed seeing 'firsts'. It could also create tensions within their relationship.

“Me and my partner didn’t get to see each other hold or care for the baby until we were home which was a crazy experience. We weren’t able to learn together or support each other. One of us was constantly missing our baby’s ‘firsts’ e.g. first bath or nappy change etc. My husband saw my baby with her eyes open for the first time and I was just so upset that I missed it and cried all night. I started to almost become jealous of my husband seeing her and became annoyed when he would arrive to see her after he finished work as it meant I would have to go home.” (Mother of a baby born in June 2020)

“Not being able to be on the ward together was so hard and definitely had an impact on our ability to gel as a family (as this was our first baby) - I felt bad for my husband for every moment I was on the ward and not him. [It] had [a] major impact on breastfeeding which in turn had an impact on my baby’s care and length of stay in hospital.” (Mother of a baby born December 2020)

Twins and Multiples

Units have told us that in special circumstances they can be flexible with the rules to meet the needs of parents. Twins and multiples are far more likely to be admitted to a neonatal unit after birth^{xxvi}, and this group of parents can be seriously disadvantaged by a policy that stipulates that just one parent can be on the unit at a time, when they have more than one baby on the unit. **28 per cent of units we spoke to continued to impose a policy that prohibited both parents being on the unit at the same time even for the parents of twins and multiples.** On those units, one parent has no choice but to split their time between two or more babies.

Restrictions that only allow one parent on the unit at a time can particularly impact the parents of twins and multiples. As discussed above, while some units who could not facilitate access for both parents of one baby together amended their policy to enable ‘one parent per cot’ for parents of twins or multiples, this is not always the case. Parents in this position have often had to choose how to split their time between babies, with neither baby getting as much contact with a parent as the parent would like.

“[It] was horrific. I felt like I had no support and had to split my time between both babies so felt guilty if I spent time with one & not the other as they were in different rooms.” (Mother of twins born before March 2020)

“[Neonatal] is a tough journey, but doing it alone is really tough - especially when you’re trying to split your time between two poorly babies and constantly feeling guilty if you held one then one was on their own.” (Mother of twins born in August 2020)

Critically ill babies and babies receiving end of life care

All of the units we spoke to said they would flex their parent access policy if a baby was critically ill or receiving end of life care, even if their policy did not currently allow parents to have full access together. However, the extent to which these policies are altered by units in these situations is variable and ranges from full family involvement (including siblings and wider family) to small flexibilities such as parents being able to be present more than once per day. While it is welcome that units aim to adapt their policy when a baby is critically ill or receiving palliative care, some babies will decline very quickly. Parents may have missed out on days or weeks or more of being with their baby regularly before their baby dies. For babies who die on the neonatal unit, opportunities to be actively involved in daily care and decision making throughout admission is a crucial aspect of memory making, and precious time they will never get back^{xxvii}.

“We couldn’t have visitors, no end of life support, no proper funeral, no after death support at all for the father (me) and my partner’s was only a phone call.” (Father of a baby who was born before March 2020, who died in neonatal care)

"[Wearing a mask] felt horrible like I couldn't talk to my baby how I wanted to my anxiety was bad at the time and I couldn't breathe." (Mother of a baby born in August 2020, who died in neonatal care)

"[There was] no access for family members except when death was imminently expected and then it was only one at a time." (Father of a baby born in October 2020, who died in neonatal care)

"Our oldest son was never allowed in to see our baby even though this was requested on multiple occasions. Our son was asking to see him and we felt this was the only thing that would help him and offer some understanding." (Mother of a baby born in July 2020, who died in neonatal care)

[My partner]... missed tube feeding, holding them for the first time, them moving from ventilators to CPAP... getting dressed for the first time, being bathed, them having their first bottles and coming away from their NG tube. Not to mention 6 lifelong diagnosis of conditions, 10 blood transfusions between them, two bouts of sepsis, hundreds of heel pricks/blood tests/immunisations, countless times they both stopped breathing... I had to do this entirely on my own.. I couldn't tell him how bad a day had been truthfully because I never wanted him to panic, since he still wouldn't be allowed to visit. (Mother of twins born in March 2020)

Personal protective equipment

As the pandemic has progressed and wearing Personal Protective Equipment (PPE) such as face coverings has become the norm in wider UK society, many neonatal units have also introduced a requirement for parents to wear PPE. This has been implemented in a variety of ways and parents most often told us that they were asked to wear a mix of face coverings, gloves and aprons.

The majority of neonatal units that we spoke to (76 per cent) said that parents must wear PPE at their baby's cot-side on their unit, and **almost half (47 per cent) were unable to allow parents to take off PPE even when they held their baby.**

We asked parents an open-text question about the impact that wearing PPE had on them, and received 399 responses. Around one third of these parents told us that they understood the need to wear PPE – even if they also expressed discomfort or concerns about wearing it - to keep their baby, staff on the unit and themselves safe, and were satisfied with this, especially if it meant spending more time with their baby and keeping everyone on the neonatal unit safe.

"I couldn't kiss my baby or even smell him or just simply rest my cheek on his head. I felt like I had a lot taken from me having to wear ppe. I understand it was for everyone's safety but still it was awful." (Mother of a baby born in May 2020)

"[It was] understandable, but when sat holding baby away from others it would have been nice to not wear the mask." (Mother of a baby born in December 2020)

"The reasons are understandable. You're protecting your child and the nurses & staff looking after them." (Mother of a baby born in November 2020)

However, more than two-thirds of parents that answered this question expressed their distress at having to wear PPE, and in particular parents were concerned about wearing PPE while sat at their baby's cot-side, and while holding their baby and taking part in their care.

Parents highlighted their concerns about the impact on them and their baby, including bonding, development, and breastfeeding.

"I have never smelled or kissed my own baby, he has never seen my face and might not for months. It's heartbreaking." (Mother to a baby born in October 2020)

"I felt like I wasn't able to relax- I was hot and uncomfortable. I felt like when I was holding my baby it was impacting on us bonding. We would try to have skin to skin but I would have to wear gloves so she couldn't feel me stroking her. Her skin would get stuck to the apron I was wearing. I couldn't look down at her properly when she was in my arms as the mask was in the way. (Mother of a baby born in June 2020)

"Unable to bond with my baby in key moments, like my baby didn't belong to me and I wasn't safe for my baby." (Mother of a baby born in July 2020)

"[I felt] Cut off from my baby. She's 8 weeks old and I haven't kissed her yet." (Mother of a baby born in November 2020)

Parents told us that they were particularly concerned that wearing face masks all the time would affect their baby's development as they could never see their face. They were also concerned that their baby would not recognise them without a mask and could not tell the difference between a parent and healthcare professional.

"[I felt] Distant, unable to bond properly, worried he won't know who his parents are or recognise our smell, touch or faces." (Mother of a baby born in September 2020)

"[I felt] Upset because it limited interaction with my baby and it worried me because I felt that this could have a negative impact on bonding and social development." (Mother of a baby born in July 2020)

"Felt worried that my baby couldn't see our faces so wouldn't start to recognise us as mum and dad. Also sad that he wouldn't be able to pick up on facial expressions such as smiles." (Mother of a baby born in June 2020)

"I worried he would not see facial cues and begin to recognise my face." (Mother of a baby born in October 2020)

Parents told us that their ability to breastfeed was affected by PPE, as many mothers were asked to wear masks – and sometimes gloves and aprons - while they breastfed their baby. Parents said that they couldn't see their baby while they breastfed, making it harder to establish feeding successfully.

"It was especially difficult trying to breastfeed too as trying to get the baby to latch on when your eyes get covered by the mask when you look down was really tricky and I ended up bottle feeding in the end." (Mother of a baby born in July 2020)

"In neonatal unit I had to wear a mask. This made breastfeeding very difficult and affected skin on skin. I hated the mask, I'd get hot and struggle to look down at my baby when trying to breastfeed. It made me frustrated and sad." (Mother of a baby born in July 2020)

"It felt like a barrier between me and baby and also unsafe wearing a face mask while breastfeeding/ skin to skin as it made it very difficult to see baby and know how baby was responding or if there were any colour changes etc." (Mother of a baby born in May 2020)

Breastfeeding is also something that units told us was severely affected by general restrictions on units, with one LNU telling us:

"We stopped rooming in for a month in March 2020. Our exclusive breastfeeding rates dropped by half during that time."

Parents sometimes felt that some rules around PPE were too strict or applied in a way that did not make sense to them. This was particularly felt when they were asked to wear PPE while breastfeeding or having skin-to-skin, even if the parent in general felt that wearing PPE was necessary.

“Not ideal, but worth it to protect children and staff. My wife having to wear an apron while breastfeeding was perhaps a little mad.” (Father of twins born in March 2020)

“I felt that it hindered the bonding between myself and husband and our babies and was pointless in the sense that skin to skin and breastfeeding etc. were still very much being encouraged so wearing mask gloves and apron to then put baby on your skin or on breast made little sense to me.” (Mother of twins born in May 2020)

“I’ve got used to it now but initially I couldn’t even kiss my babies; heads. It was heartbreaking, I could have skin to skin but still [had to] wear gloves and couldn’t hold their hands other than with gloves on. It made no sense.” (Mother of twins born in July 2020)

“It was ridiculous as I was allowed to have skin to skin contact and breast feed but had to wear mask, apron and gloves... even during skin to skin and feeding!” (Mother of twins born in May 2020)

Parents used words like ‘claustrophobic’, ‘detached’ and ‘uncomfortable’ to describe the experience of sitting for hours on end at their baby’s cot-side in PPE. Neonatal units are kept warmer than other parts of the hospital and this was highlighted by parents as being something that made wearing PPE – which in general they often found uncomfortable – much worse.

“Claustrophobic, hot, flustered and like I was dirty and harbouring germ.” (Mother of a baby born in April 2020)

“Horrible. Hot. Sweaty. Hard to breathe. Panicky. Anxious” (Father of a baby born in July 2020)

“[I felt] overheated, dehydrated, a bit isolated, made it harder to communicate.” (Father of a baby born in October 2020)

“Sometimes with the heat on the unit in the summer, the masks were too much to bear and made some of my visits uncomfortable. [It] got annoying since I seemed to spend more time focusing on not being able to breathe than spending quality time with my babies.” (Mother of twins born in May 2020)

Parental isolation and mental health

New parents across the UK have found the COVID-19 pandemic an isolating timexxviii. But for parents of babies in neonatal care, there is added pressure as they try to navigate neonatal units alone, without the support of partners, family and friends. **92 per cent of parents told us that they felt more isolated as a result of the pandemic**, and 51 per cent described themselves as ‘very isolated’.

For the parents who responded to our survey these feelings of isolation were universal, with the response to this question remaining consistent regardless of the length of time that a baby spent on the unit, or the access policies experienced.

Having a baby who is admitted to neonatal care is very stressful and traumatic for parents, and they often need emotional support to help them cope. Parents of babies receiving neonatal care are more likely to experience mental health problems as a result of their experience.

Research shows that mothers of babies who are admitted to neonatal care are up to 40 per cent more likely to suffer from post-natal depression and other mental health conditions compared to mothers in the general population.^{xxix} Parents with existing mental health problems prior to the birth of their baby may have these exacerbated by the trauma of birth and the experience of having a sick baby.

As such, it is important that families receive support throughout their journey, including post-discharge, from professionals who have experience of working with families affected by neonatal care, and that services are organised so families who may face regular ongoing hospital appointments and re-admissions are able to access the support they need.

69 per cent of the parents we surveyed said their mental health has got worse as a result of their neonatal experience and 56 per cent said the mental health of their partner and wider family has been affected. This experience was exacerbated by the length of time their baby spent on the unit, **70 per cent of parents whose baby was on the unit for more than 4 weeks said that their mental health was worse, in comparison to 63 per cent of those whose baby spent less time on the unit**, and the experience was also more acute for the small cohort of parents who were still on the unit (n=74), with 79 per cent of these parents reporting that their mental health had been made worse by their baby's neonatal admission.

Parents who experienced restrictive parental access policies were more likely to report that their mental health had become worse with **72 per cent of parents who could not be on the unit at the same time as their partner saying their mental health and well-being had been affected**, in comparison to 60 per cent of those who could care for their baby with their partner. **74 per cent of parents whose baby spent time on a unit where time-limits were imposed said that their mental health and well-being had been impacted** in comparison to 64 per cent in units with no time restriction.

"It really affected my mental health. One of us would have to sit waiting to see her whilst the other was with her whilst she was very poorly/ having major procedures done." (Mother of a baby born in May 2020)

"Not being able to be with my baby brought an extra layer of anxiety making my mental health even worse. I didn't have enough time to ask questions about his care." (Mother of a baby born in June 2020)

"In the initial hospital only one parent was able to be beside each baby. This was extremely difficult and mentally tough on both of us as our babies were requiring significantly different types of care and we could only be there separately, until it was clear that our baby was not going to survive." (Father of twins born in January 2021)

"It affected mine and my wife's mental health as normally we would support each other however we weren't able to access support from wider family members during covid restrictions." (Father of a baby born in May 2020)

"I currently suffer with PND and PTSD. Having to go through this journey without the physical and immediate support of partner and family has left me in a bad place with my mental health, now even more so that the restrictions have been lifted and I know there was now no reason for that to have been the case. It hurts." (Mother of twins born in August 2020)

"Being alone in hospital with my little girl has a bad effect on my mental health when something doesn't go as expected and it makes me feel very alone, and gives me a lot of guilt especially when I have to leave the room to telephone my husband and update him with what is going on." (Mother of a baby born in August 2020)

Unfortunately, support for the increased risk of mental health conditions is not always available to parents in the high-risk setting of the neonatal unit. Despite national guidance outlining the need for psychological support for parents, this aspect of family care did not have the funding needed to match demand even before the pandemic. In spite of the additional pressures placed on many parents experiencing neonatal care during the pandemic, the necessary resources have not been put in place to manage increased demand for mental health support. The results of our survey show that parents

found the support they needed was not always available to parents in this setting. **47 per cent said they were not offered support for their mental health while their baby was in neonatal care** and 28 per cent said they really needed support for their mental health and wellbeing while on the unit but couldn't access it.

This lack of appropriate support continues into the community with **half (49 per cent) of those whose baby had been discharged not being offered mental health and wellbeing support in the community** and 22 per cent who felt they really needed mental health or wellbeing support after discharge could not access it.

Parents of babies born premature or sick experience stressful and sometimes traumatic situations and some parents will need appropriate specialist mental health support as a result. Services to support this need to be available in a way that works for parents while they're on the unit and in a way that does not let parents fall through the cracks once their baby goes home.

Parents told us that mental health support was not there when they needed it or was inappropriate to support them with the experiences they had in neonatal care.

"Due to covid mental health help was advised but not accessible or has been delayed." (Father of a baby born in May 2020)

"It was offered at the wrong time. There was no persistence. I suffered mentally by myself for a long time. By the time I got help, I had overcome much of the hurdles myself." (Mother of a baby born in April 2020)

"My husband was offered help as the mental health team did their rounds in an afternoon when he visited. I visited in a morning and never saw anyone." (Mother of a baby born in April 2020)

"Nothing was ever mentioned about me, as I didn't get to see my baby for over a month. My wife had to take all the bad days on her own and I guess she was my priority." (Father of a baby born in March 2020)

"I was offered counselling which I tried but felt like she couldn't understand or help what we had been through." (Mother of a baby born in August 2020)

"I wasn't made aware there was anything available, it would have been helpful as it was a distressing time." (Mother of a baby born in December 2020)

Impact on family finances

Previous Bliss research^{xxx} has shown that having a baby in neonatal care impacts on families' finances. This can have an impact on parental stress levels and can act as a barrier to parents being on the unit and as involved in their care as they would like to be. This trend has continued through the pandemic, with **36 per cent of parents saying their family finances were worse as a result of their baby's neonatal experience.**

Some units provide parents with support for some of the expenses associated with having a baby in neonatal care. This can cover things like parking or food and drink. Only 26 per cent of respondents in England, Wales and Northern Ireland said that they had been able to access this type of support for the cost of expenses on the unit. Where offered, however, this was highly valued by parents, with 68 per cent who had received support saying that this had made a positive difference to them and their family during their baby's neonatal stay.

However, **45 per cent of respondents in England, Wales and Northern Ireland had not been able to access this support but said it would have made a significant difference.** Parents told us that while

some policies relating to the pandemic had lessened the financial burden – such as removal of parking charges during lockdown – many also said that some support that would usually be available (e.g. free or discounted meals from the canteen) were not available because of the pandemic. For parents without access to a car, the guidance not to use public transport could make travelling to the hospital (usually by taxi) even more expensive.

“I remained in hospital several days but my husband travelled back and forth and this ran finances down especially as we rely on public transport which was greatly reduced due to the pandemic” (Mother of a baby born in May 2020)

“My baby had to be born in a hospital 2 hours from where we live. Due to Covid there was no accommodation and we needed to stay in an air bnb which was expensive.” (Mother of a baby born in October 2020)

“There was support in place for us at the hospital but due to COVID we were not allowed to access this (canteen etc.)” (Father of a baby born in July 2020)

“We partly rely on benefits at present therefore travel costs were difficult to meet, it meant that I was without food during most of my visits.” (Mother of twins born in August 2020)

“We would skip meals to be careful with money and ensure we was with our son as much as possible.” (Father of a baby born in December 2020)

Financial support in Scotland

In many parts of Scotland, the low population density means that many parents have to travel particularly far to be with their baby on the neonatal unit. Our research^{xxxi} previously showed that the cost of travel affected how often a parent could be with their baby on the unit. As a result of our campaigning, in 2018 the Scottish Government acknowledged the financial impact of a neonatal stay on families in Scotland and introduced the Neonatal Expenses Fund (NEF). The NEF is a fund for families with a baby receiving neonatal care to be reimbursed for the cost of food, drink and travel. It can also be used for accommodation at the discretion of the Health Board. During the COVID-19 pandemic, this was extended to cover the cost of taxis – to reduce parents’ exposure to the virus on public transport.

67 per cent of the parents we spoke to who lived in Scotland said that they had been able to access support with expenses. Of those who could access this support, 79 per cent said it made a positive difference to them and their family. This is a substantial endorsement of the Neonatal Expenses Fund in Scotland. For example, one parent said:

“It’s an expensive time having a baby and the additional travel costs build up but being able to apply to receive some of the costs back was helpful.” (Mother of a baby born in August 2020)

However, some parents that we spoke to had been unable to access the scheme, with 24 per cent saying this support would have made a significant difference to them if available. Some comments around this question indicate that communication about the scheme could be better.

“Months after our babies got home we found a form in amongst paper work offering travel and food expenses but when given this paperwork it was never explained to us that this form was in there and by then it was too late.” (Mother of twins born in April 2020)

“We paid for our own petrol and food/drink from shops when we were at hospital. We didn’t get round to filling out the forms to claim travel expenses as we didn’t know where to find them despite it being mentioned at the very start when we were processing everything else being told to us.” (Mother of a baby born in June 2020)

The role of neonatal staff in supporting parent and family well-being

Throughout the responses that we received there was a key theme relating to the overwhelmingly positive role of staff in supporting families while their baby or babies were on the unit. Parents told us how extremely grateful they are for the care that their babies have received and for the teams of healthcare professionals that delivered it. The positive impact of staff on the neonatal unit was felt throughout their journeys and is reflected in the responses to our survey. When parents have been alone on units, feeling lonely and helpless, the neonatal workforce has stepped in to provide them with the comfort and support that they needed.

"The neonatal unit was fantastic under the circumstances and are doing a great job." (Mother of a baby born in August 2020)

"The staff were very approachable, could chat like we had been friends for years. Made the time sitting next his bed go fast and put us at ease." (Father of a baby born in December 2020)

"Our mental health has been impacted significantly, however due to the staff in both hospitals it isn't as bad as it could have been as they have been exceptional." (Father of a baby born in January 2021)

"I do feel the teams at both hospitals have great empathy for parents in relation to the covid restrictions and knowing that your feeling towards them were justified was a huge help. They were never imposed rudely or harshly just in order to ensure safety against covid which is no one's fault." (Mother of a baby born in October 2020)

"I would like to thank the neonatal team a huge thank you. The care we received from them was outstanding. They care for your baby as if it was their own and got their best interests at heart. The care was second to none. The staff were friendly and were there to talk to you if you were feeling down. Nothing was ever too big an ask to them. Amazing." (Mother of twins born in July 2020)

"We are very grateful for the care our son received in a very difficult time in the world." (Mother of a baby born in June 2020)

Improving parent access

Neonatal units in England

In December 2020, NHS England published guidance to support Trusts to return to full access for parents. The guidance states clearly: *“Parents of babies in neonatal critical care need to be involved in their baby’s care as much as possible. Integral to this is ensuring parents have access to their baby... Parents are partners in care and should not be considered to be visitors”*. To support units to facilitate full parental access, there are three actions that Trusts are asked to undertake. These are: conducting risk assessments; assessing and changing unit layouts to help with distancing; and testing parents for COVID-19.

We asked NHS Trusts in England to tell us about the actions that they have taken in response to the guidance and how this has impacted their access policy.

i. Risk assessment

The majority of Trusts (80 per cent) have undertaken risk assessments to identify whether there was a risk of transmission by having both parents present on the unit, and a further 6 per cent were currently in the progress of doing this. We also asked whether the impact of separation on the baby and family had been looked at and included in the formal assessment. While many units said they had considered this, a substantial minority (35 per cent) had not included this in a formal assessment. Trusts were even less likely to have conducted an equality impact assessment – with just 28 per cent of units who had completed, or were in the process of completing, a risk assessment having included an equality impact assessment.

ii. Unit Layout

Most (86 per cent) of the Trusts that we spoke to said that they had assessed their neonatal unit layout. **However, 63 per cent had identified that layout changes would not affect their parent access policy. Just 23 per cent had been able to make changes to their layout that enabled them to improve their policy as a result.** Higher level units (NICUs) were better able to make changes that materially impacted the parents of babies on their units, with SCBUs (the lowest level of care) who usually have the smallest footprints, the least likely to be able to do this.

iii. COVID-19 testing

Units were asked to use spare testing capacity to test parents to help return them to units. Of the units we spoke to **43 per cent were not able to regularly test parents** and 36 per cent said they were regularly testing parents – with the majority of other units working towards testing but unable to comprehensively offer it at the time of our survey (March 2021).

In the open-text answers for this question, some units who were not currently testing parents told us that their Trusts were testing mothers on admission to maternity, sometimes testing partners at the same time, but were not testing based on admission to the neonatal unit. Others were taking a screening approach which included asking parents to declare any COVID-19 symptoms or have their temperature taken on arrival at the unit. Some units also reported that protocols for testing were going through their internal process, and for some that meant that once in place restrictions would be loosened.

However, of the 25 units who were testing parents regularly, only 7 (28 per cent) of these were able to facilitate full 24-hour access for both parents, together, at their baby’s cot-side. From this we know that testing has not always provided the opening up that the guidance intended, and comments from Trusts show that a negative COVID-19 test is not always seen as sufficient to enable full access. A unit, not currently offering testing, or supporting parents full access to their baby said:

“We believe COVID-19 testing is not currently required as known negative status would not mean visiting restrictions could be altered.”

What are the barriers to returning to full parental access?

We asked Trusts to tell us about the key barriers they were facing to implementation of 24-hour access for parents. Of those who identified a barrier, the overwhelming majority said this was about the physical space of the unit and maintaining social distancing was the key issue. Other barriers described in survey responses include wider Trust visiting policies and being unable to implement COVID-19 testing for parents.

“Cot spaces are close to each other and when activity levels increased, inability to maintain 2m rule.”

“A review of each area of the unit has been undertaken and areas between cots measured to ensure 2m distancing and an assessment of how many visitors can be in each area at one time to allow socially distancing and avoid overcrowding and risk of transmission.”

Planning to return to full parent and family access

The pandemic has presented a fast-moving, ever-changing environment in which neonatal units must operate. National lockdown restrictions have varied across the country and changed at regular intervals and in response many neonatal units have regularly, sometimes continuously, reviewed their restrictions alongside this. How regularly restrictions are reviewed varies widely between units, however. Amongst the units that we spoke to, units were most likely to be reviewing their access policies whenever there were changes in national guidance from government and NHS England as well as from organisations such as BAPM, Bliss, and regional and local bodies.

Some neonatal units were reviewing their policy on a more predictable basis e.g. once per month or once per week at regular organisational meetings, and some reviewed daily. Units that reviewed their policy daily were usually smaller units that could flex their access policy depending on cot-capacity and how many parents were intending to be present on the unit that day. This minimised the amount of time that the unit had to impose restrictions on parent access and enabled them to react quickly when the team felt that the unit was becoming too crowded to maintain a social distance.

Neonatal units also told us if and how they were looking ahead at returning to usual access for parents and wider families. **Of those neonatal units who could not currently facilitate full parental access, 43 per cent did not currently have a plan in place to facilitate a return to unrestricted access for both parents,** 21 per cent were currently working on one and 36 per cent had one in place.

Units gave us further details about their intentions to return to full access as well as when they thought they may be able to put a plan into place. The two most common themes were around the government road map and general easing of restrictions, and COVID-19 testing. Both areas present clear opportunities for government and national bodies to drive improvements in practice over the coming weeks and months.

Governments in the four nations of the UK have taken different approaches to publishing their plans for lifting restrictions on the wider population, but they have all started to lift measures and have published plans with clear dates either for lifting of certain restrictions or to review the alert level that their country is currently subject to. England and Scotland both have Roadmaps clearly defining when and how restrictions are likely to be eased, Wales has published a Coronavirus Control Plan outlining clearly each alert level in Wales and what type of restrictions can be lifted in each level, and Northern Ireland has similarly published plans and review dates for returning to usual.

Our research shows that units are looking towards these documents about wider restrictions, which do not specifically give guidance for neonatal settings, to guide when they should consider easing restrictions on neonatal units. Indeed, some units told us that they are already following, or in the process of developing, their own roadmaps – aligned with national guidance – to help them return to usual practice. Without specific guidance for units on what each new step out of lockdown means for them, however, the variability that we have seen throughout the pandemic on neonatal units will continue into the recovery. It would therefore be a missed opportunity not to publish a neonatal-specific recovery roadmap at national level, in each of the four nations, and is likely to allow the high variation in parental access to continue far longer than necessary.

Conclusion

Our findings support the existing literature which shows that neonatal units have had to restrict access for parents of the babies in their care, and that this is having a severe impact on babies and parents. It is important to babies' outcomes that their parents are involved in their care, and the COVID-19 pandemic has meant that parents are not able to be there as much as they want and need to be.

The restrictions imposed vary widely from unit to unit. Although 24-hour access is now granted to parents individually in many units, the fact that parents are often unable to be together at the cot-side means parents are frequently alone without support, wearing a mask and other PPE. Parents feel that this has had a considerable impact on their ability to be involved in their baby's care, to bond with their baby and as a family, and has had a detrimental impact on their mental health.

The response from national governments and NHS bodies has been varied. In Scotland, the government published guidance for Health Boards relatively quickly, and has continued to update this as the guidance relating to COVID-19 for the general population has changed over time. There is now national guidance in Scotland to return siblings to units. In Wales and Northern Ireland, national governments have endorsed a one parent policy that treats parents as visitors, when we know that this should never be the case. In England, there was a vacuum in national leadership for the first nine months of the pandemic, allowing a high level of variation in practice to bed in.

Now, national governments and NHS bodies across the UK must take action to return parents to neonatal units and give local health services the tools they need to return to usual practice. Learning from the pandemic must also be used to inform any future response to similar events to prevent the avoidable harms of separation occurring.

Recommendations

1. Immediate action is needed at a national level to ensure that the transition back to usual parent access is consistent across each country and that Trusts and Health Boards are supported to re-establish usual levels of family support and involvement as soon as the external context allows. NHS England and the Scotland, Wales and Northern Ireland Governments must each publish a National Neonatal Roadmap setting out how neonatal units will return to usual family access, which must:

1.1. Provide Trusts and Health Boards a clear timetable to facilitate both parents, or one parent and a nominated support person, to have unlimited 24-hour access to their baby, together on neonatal units as soon as possible.

1.1.1 Include details for siblings to return to neonatal units to support whole-family care and bonding, as well as facilitate better access for parents with other children at home.

1.1.2. Include details for expected return of wider family (excluding support persons) and visitors to neonatal settings

1.1.3. Mandate that parent and sibling access restrictions do not continue beyond the final date, as set out by each Government, for the removal of all legal limits on social contact

2. NHS England and the Scotland, Wales and Northern Ireland Governments to provide clear guidance for Trusts and Health Boards to ensure neonatal services are facilitating one metre plus social distancing rules when other mitigations, including face coverings and negative COVID-19 tests, are being utilised.

3. The Departments of Health in both Wales and Northern Ireland must immediately ensure that all national guidance takes a family centred approach to neonatal care. They should do this by:

3.1. Updating relevant visiting guidance to ensure that there is no blanket national policy to prevent parents caring for their baby together on neonatal units at any level of national restrictions.

3.2. Ensure national guidance reflects BAPM and Bliss recommendations which detail that parents are not visitors to neonatal units, and that parents and nominated support people should be given full access to their baby, including caring for their baby together.

3.3 Update national guidance to make clear that, if there is clear evidence that restrictions are required, parents and nominated support people must be offered the opportunity to regularly be with their baby together for extended periods of time.

4. In line with existing national guidance, Trusts and Health Boards should never consider parents as visitors to a neonatal unit and should therefore not apply wider hospital visiting guidance to parents of babies receiving neonatal care. They must support neonatal units to:

4.1. Immediately implement interim measures to mitigate the impact on babies and their families if there is clear evidence that restrictions are required at the present time, including:

4.1.1. Offer all parents the opportunity to routinely care for their baby together for extended periods of time if parents are not currently able to be present together at all times of day.

4.1.2. Support both parents to regularly attend and participate in ward rounds together. Every effort should be made to communicate any significant news about their baby's condition or care to both parents, preferably when they are together.

4.1.3. Enable parents to remove masks and other PPE (such as aprons and gloves) while they provide care at their baby's cot-side, including skin-to-skin, kangaroo care and feeding, to support their babies' development and bonding, unless this would necessitate the reduction of parental presence.

4.1.4. Facilitate simultaneous access for parents (and their nominated support people) of twins and multiples, so that one parent does not have to split their time between two or more babies.

4.1.5 If a baby is critically ill or receiving end-of-life care ensure everything possible is done to enable both parents (including those who are COVID-19 positive) and siblings to be present and involved in decision making, care and memory making. Consideration should also be given to enabling access for wider family where appropriate.

4.2. Regularly review parental access policies to ensure they are facilitating as much flexibility as is possible to be accommodated within the local health context, with a view to returning to full parental presence on the unit as soon as possible.

4.3. Include an equality impact assessment and an assessment of the impact of separation to babies and parents on bonding and mental health as part of any risk assessments taking place on the neonatal unit.

4.4. Proactively use daily, routine data collection gathered for the National Neonatal Audit Programme reporting, such as parental presence on ward round figures in order to assess compliance with best practice at a Trust and Network level and to drive change

5. To maximise opportunities for involvement in care and decision making for parents and family members, particularly where full-unrestricted access is not in place, neonatal units must:

5.1. Ensure parents on the unit are signposted to and encouraged to engage with appropriate emotional and psychological support while their baby is receiving neonatal care

5.2. Ensure that any parent who cannot attend the unit regularly, including as a result of access restrictions, is able to access and is encouraged to engage with, appropriate emotional and psychological support and is given specific support to bond with their baby.

5.3. Put in place processes to ensure that both parents are fully involved in decision-making about their baby's care, kept up to date with their progress and can ask questions of their baby's medical team.

5.4. In England, work with Care Coordinators to monitor and adhere to national guidance across Operational Delivery Networks

6. Governments and NHS bodies must develop clear action plans to mitigate the impact of further lockdowns or future pandemics on neonatal services. Plans should be developed in partnership with neonatal networks, neonatal units and service users. They should take a family centred approach, prioritising parents' access to their baby and involvement in their care, and acknowledging the harm to babies of separation from their parents.

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