Zero separation. Together for better care!

Infant and family-centred developmental care in times of COVID-19 – A global survey of parents' experiences







In cooperation with











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Contributors

The report was written by Johanna Kostenzer, Charlotte von Rosenstiel-Pulver, Julia Hoffmann, Aisling Walsh, Sarah Fügenschuh, Aurelia Abenstein, Luc J.I. Zimmermann, and Silke Mader, and designed by Diana Hofmann-Larina (all EFCNI).

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Foreword

Globally, 2020 is a year that will not be forgotten in living memory and no doubt, will go down as a marker in recent history. The COVID-19 pandemic has and is still disrupting societies around the world – socially, economically and politically. It has caused death, devastation and serious sickness for millions, with the full effect of the long-term consequences yet to be seen. At its core has been the focus on healthcare systems and the associated strain on healthcare workers around the world. While the focus has, quite rightly, been on managing the COVID-19 crisis and its fallout, pandemic-related restrictions have also affected quality of care, including infant and family-centred developmental care (IFCDC).

For us, at EFCNI, IFCDC is core to the very ethos of our foundation. When the pandemic hit, we grew increasingly concerned about the impact on the provision of care to preterm born, sick and low birthweight babies in neonatal intensive care units (NICUs). Parents having inadequate access to their child had been voiced as a concern by several of the parent organisations in our network in Europe and across the globe. Taking this perspective as our guiding principle, we carried out a multi-national survey among parents with babies in NICUs around the world during the pandemic, which enabled us to comprehensively share their experiences within this report.

Despite important advances in maternal and newborn care in the last decade, preterm birth remains high across the globe, with one in ten babies being born too soon. This and complications arising from preterm birth remain the leading cause of neonatal death. The United Nations' 2030 Sustainable Development Goals include the end of preventable deaths of newborns and children,¹ and the United Nations Convention on the Rights of the Child (UNCRC) and the European Association for Children in Hospital (EACH) both underline the right of children to be close to their parents. Yet, what the report shows is that more often than not, parents were separated from their babies due to restrictions that were quickly implemented as a response to the pandemic in an effort to reduce transmission of the virus. Whilst we most certainly agree that restrictions were necessary to manage the COVID-19 situation, the pace and blanket coverage of these has had negative short, and potentially also long-term effects, on parents of vulnerable newborns.

With this report, we shine light on parents' experiences of the restrictions on IFCDC during the COVID-19 pandemic generally and also in the individual countries. Moreover, we hope to offer insights that can impact how future emergency or unforeseen situations are approached in relation to IFCDC. The evidence produced by this report strengthens our position as we continue to advocate for a zero separation policy of babies from their parents/caregivers in hospitals. And this, ultimately, is in the name of giving all babies the best possible start in life.



She Now

Silke Mader Chairwoman of the EFCNI Executive Board



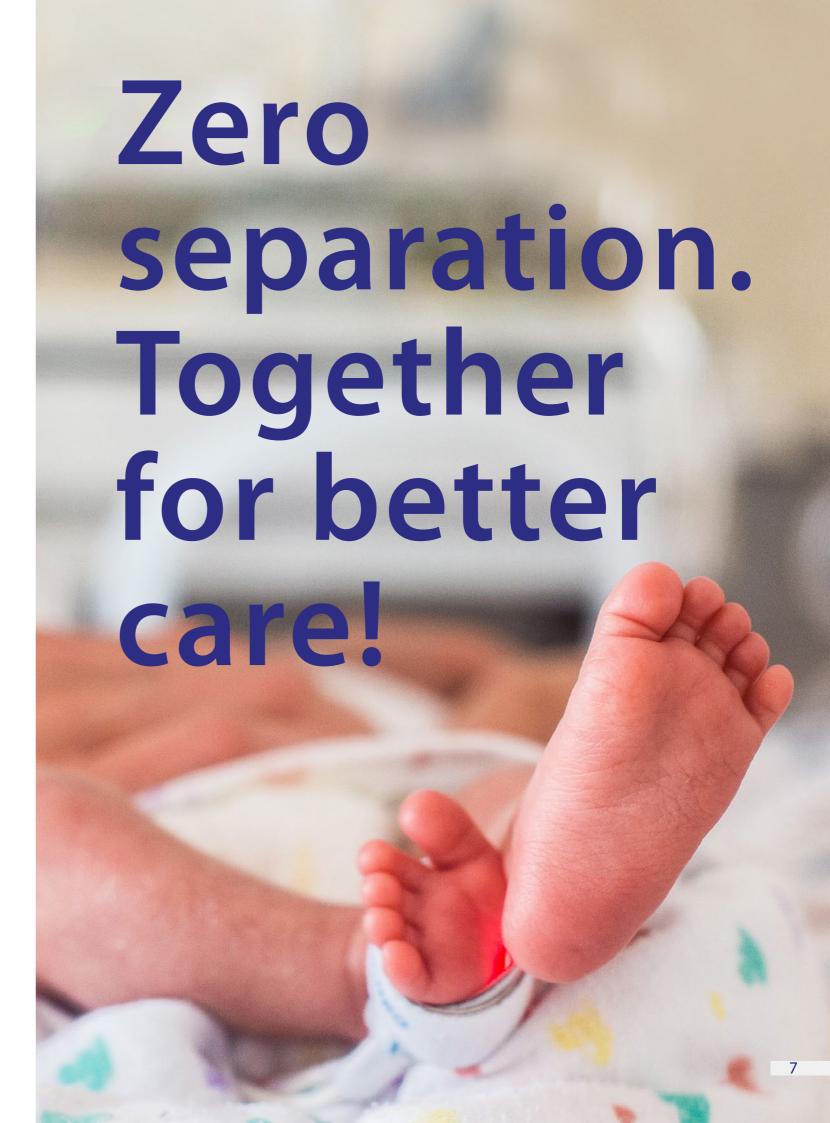
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Professor Luc Zimmermann Senior Medical Director



Channa dostense

Dr. Johanna Kostenzer Head of Scientific Affairs



Statement by the EFCNI Parent Advisory Board

When we initially started to become advocates for preterm babies and their families within our national parent organisations, we aimed to make parents equal partners in the care of their preterm or sick newborn infants. Over the years, hard work, joint forces, lobbying and persuasive efforts, as well as international research findings stressing the importance and benefits of an infant and family-centred developmental care approach, have all contributed to better care and improved the situation for many families in Europe and worldwide. Although we knew that we still had a long way to go in terms of zero separation of infants and families in the neonatal unit, the COVID-19 pandemic and implemented restrictions feel like a setback to what has been accomplished to date.

The COVID-19 pandemic poses an unprecedented threat to health professionals who try to stem virus transmission while simultaneously providing best quality care. However, in accordance with the Charter of the European Association for Children in Hospital (EACH) and the United Nations Convention on the Rights of the Child, quality care for infants must involve parents. Evidence-based cornerstones in neonatal care, for example, the implementation of kangaroo mother care to encourage family-infant bonding, the prioritisation of mother's own milk, as well as the attainment of respectful and supportive care during pregnancy, labour and birth, including the presence of a partner or loved one, have largely been suppressed in times of COVID-19 as this report shows, making parents and their infants the bereaved of this pandemic.



Following the invitation of EFCNI and GLANCE, we were happy to support this global initiative to explore parents' experiences regarding neonatal care during the COVID-19 pandemic. We want to thank all parents who replied to our appeal to participate in the survey and are amazed by the international response. Parents, more than ever, need a voice when their right to be with their baby is undermined and information is lost due to restrictions in place. In line with the WHO Baby Friendly Hospital Initiative and the UNICEF Mother Friendly Hospital Initiative, parents are not visitors and should be welcomed at the neonatal intensive care unit 24/7 to protect breastfeeding, kangaroo mother care and rooming in. They play a key role in the care of their newborns and listening to them is crucial to provide adequate and respectful care in the current but also future public health emergencies. Every newborn has the right to the best start in life, a right that is only met if parents are right by their side.

The Parent Advisory Board (February 2019 - January 2023)



Oleksandra Balyasna Early Birds (Ranni Ptashky), Ukraine



Selina Bentoom African Foundation for Premature Babies & Neonatal Care, Ghana



Livia Nagy Bonnard

Melletted a Helyem Egyesület - Right(s)

Beside You Association, Hungary



Mandy Daly Irish Neonatal Health Alliance, Ireland



Paula Guerra XXS – Associação Portuguesa de Apoio ao Bebé Prematuro, Portugal



Gigi Khonyongwa-Fernandez

NICU Parent Network,



Alison McNulty TinyLife, Northern Ireland, United Kingdom



Nina Nikolova Our Premature Children Foundation, Bulgaria



Asta Radzevičienė Neišnešiotukas, Lithuania



Dr Eleni Vavouraki Ilitominon, Greece



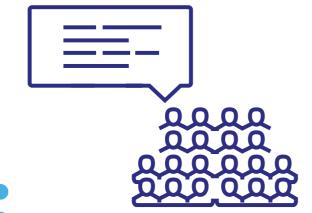
Statement by the GLANCE Chair Committee

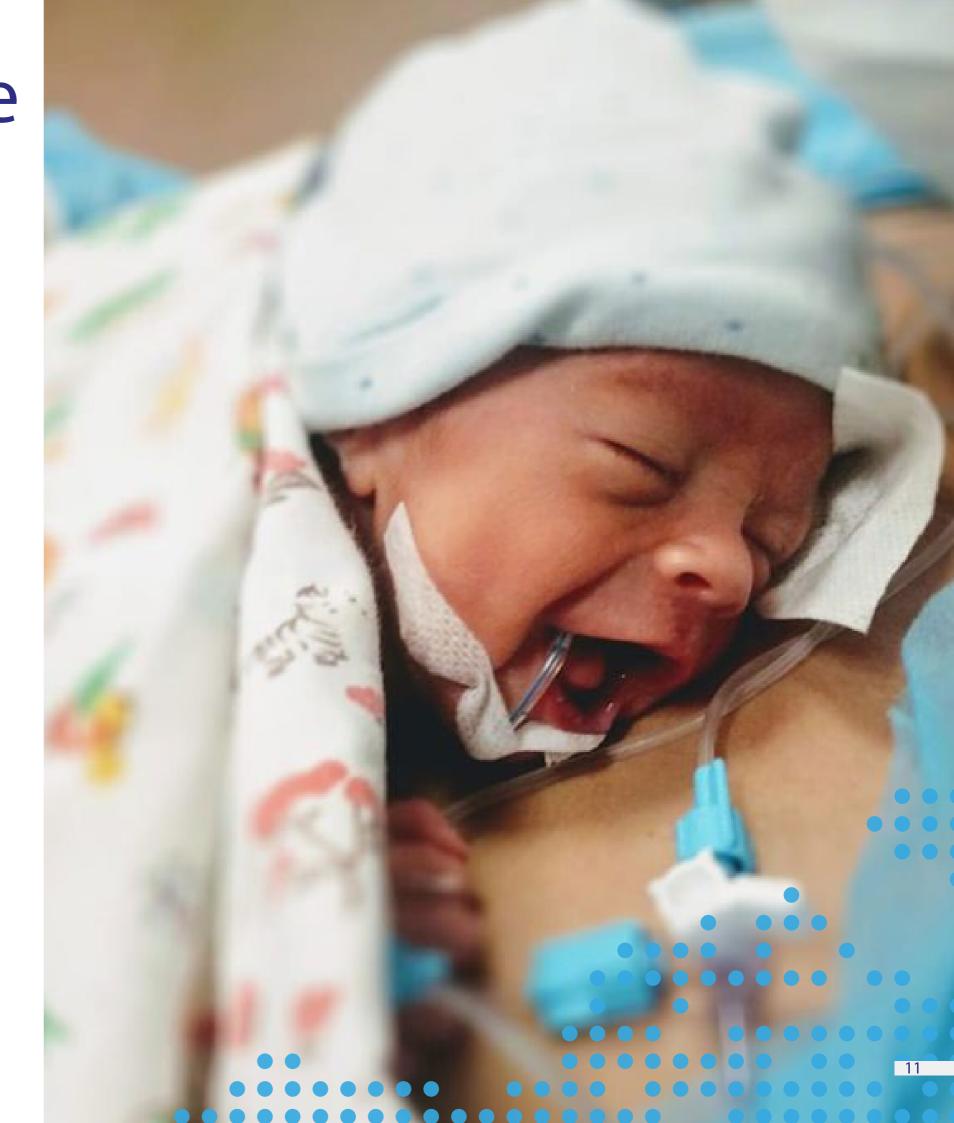
In 2019, we joined GLANCE, the Global Alliance for Newborn Care. We, that is a 20-member committee, driven by the vision of giving every newborn the best start in life. It was our aim from the beginning to let our experience as healthcare professionals, researchers, parent representatives, and former preterm infants enrich the agenda setting process for GLANCE. And then 2020 came and made clear that no matter how well you plan, when a global player like a pandemic rewrites the rules, one has to adapt.

At an early stage, we became aware of the concerns of parents of hospitalised newborns worldwide, who were being separated from their babies in the NICU due to COVID-19 safety measures. The "Zero separation. Together for Better Care!" campaign, launched in July 2020, was an immediate reaction to these separation policies. At the same time, neonatal care continued to be compromised by the pandemic. We had to observe a reduction in breastfeeding rates and provision of kangaroo mother care, and even a withdrawal of staff and life-saving equipment. In fact, all the aspects we wanted to protect and promote were suddenly hampered.

The idea of creating a global survey to give parents a stronger voice found us impressed immediately. Now, holding this report in our hands is an incredible feeling. We are grateful for the commitment from the project team and parents all over the world. At the same time, we are also concerned by the findings. Some results are reminiscent of a time when IFCDC had to be vehemently promoted and hard scientific facts had to be used to argue for minimum contact between parents and their sick baby. We had not expected that this point of view would take root again so comprehensively in such a short time.

However, we see this development also as an opportunity to reopen precisely this discourse on putting parents and babies back in the focus. We joined GLANCE not to hope and worry, but to act and to make a difference. Therefore, we speak up for parents, for children and families who went unheeded during this pandemic. We must put their needs back on the agenda, and therefore strongly support the call to action for zero separation.





The GLANCE Chair Committee



Dr Takeshi Arimitsu Selina Bentoom Medicine, Japan

Ilein Bolanos

Con Amor Venceras, Mexico

USA



Department of Pediatrics, Keio African Foundation for Premature University Hospital School of Babies & Neonatal Care, Ghana



Paula Guerra XXS – Associação Portuguesa de Apoio ao Bebé Prematuro, Portugal



Juliëtte Kamphuis Wilhelmina Kinderziekenhuis, The Netherlands



Gigi Khonyongwa-Fernandez **Mary Kinney** NICU Parent Network, University of the Western Cape, South Africa



Senkyire Ephraim Kumi Cape Coast Teaching Hospital, Ghana



Professor Satoshi Kusuda Professor Jos M. Latour Department of Pediatrics, Plymouth University in Kyorin University, Japan Plymouth, United Kingdom



Dr Daniel Nuzum Cork University Maternity Hospital, Ireland



Ilknur Okay El Bebek Gül Bebek Derneği, Turkey



Kylie Pussell Miracle Babies Foundation, Australia



Dr Salimah Walani March of Dimes, USA



Professor Karen Walker Royal Prince Alfred Hospital, University of Sydney, Australia



Dr Eleni Vavouraki

Ilitominon, Greece

Dr Björn Westrup Karolinska University Hospital and Karolinska Institute, Sweden



Professor Dieter Wolke Department of Psychology, University of Warwick, United Kingdom





PD Dr Dietmar Schlembach

Department of Obstetrics and

Gynecology, Vivantes Clinic





Statement by COINN, ESPR, NIDCAP, UENPS

With the mission to provide every newborn worldwide an optimal start in life, we endeavour to continually improve and advance neonatal care through our devoted initiatives. We follow this goal through close and multidisciplinary collaborations and by continuous reflections on the current state of neonatal care from different angles – from a scientific and evidence-based, practitioners' but also and most importantly from a patients' perspective. It its undisputed that the involvement of parents in the care of their beloved child is of paramount importance, and integrating infant and family-centred developmental care (IFCDC) into the core set of standards for neonatal care – in particular for the most vulnerable infants such as preterm, sick and low birthweight babies.

The COVID-19 pandemic poses an unprecedented public health threat, creating the challenge to stem virus transmission while simultaneously maintaining best quality care. The pandemic led to the implementation of a set of measures also applicable in neonatal intensive care units, including a restriction of visitation and parental presence, and leading – too often – to a separation of parents and their newborn.

Following the invitation by EFCNI and GLANCE, we have happily supported this initiative to explore the challenges caused by the COVID-19 pandemic, and to identify parents' experiences regarding neonatal care during these most difficult times. With this report, we take a step back to listen, and acknowledge the parents' essential role in the evidenced-based practice of infant and family-centred developmental care.

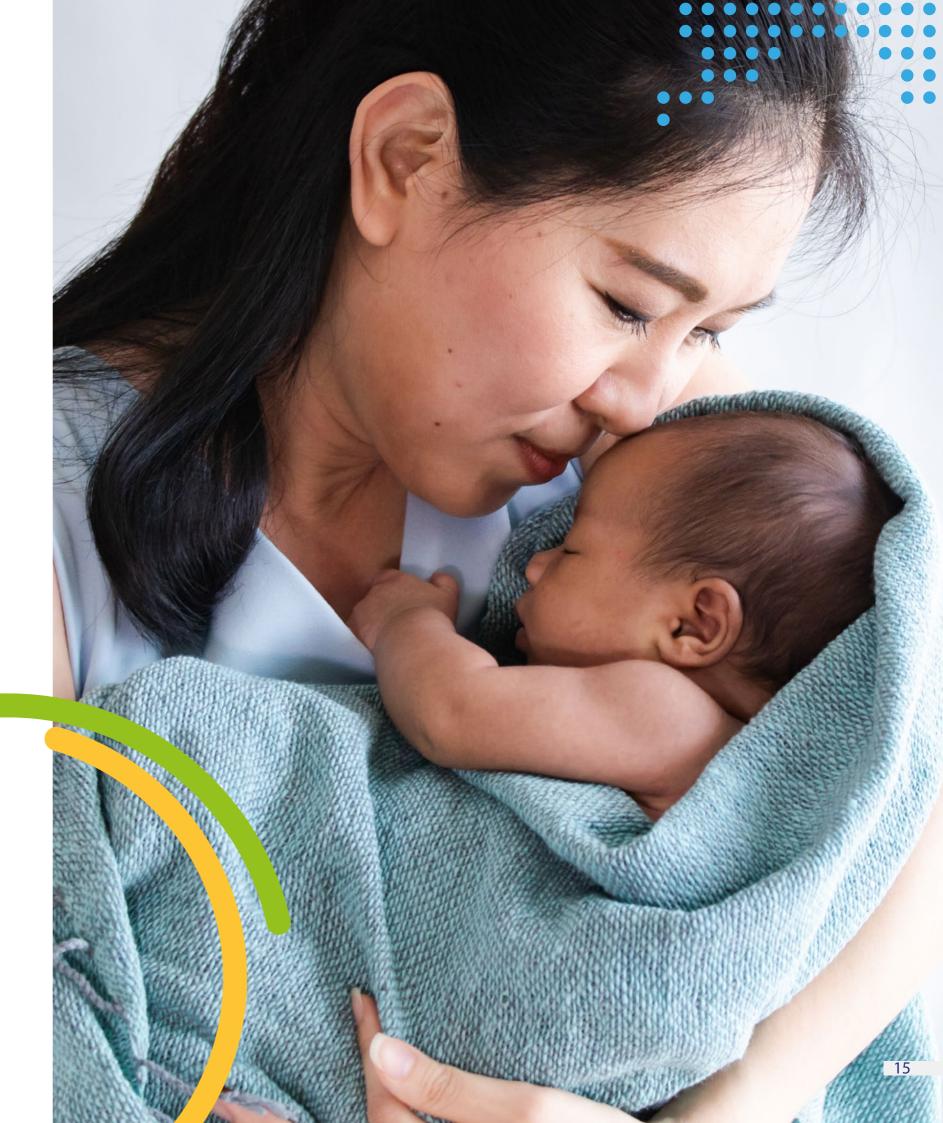
We proudly support EFCNI and GLANCE and the call for a zero separation policy to keep parents and their newborn together. Given the pandemic related challenges in neonatal care, we advocate to listen to the parents' experiences and to acknowledge their crucial role in the care of hospitalised newborns worldwide.











Abbreviations

| COINN | Council of International Neonatal Nurses |
|--------|--|
| EACH | European Association for Children in Hospital |
| EFCNI | European Foundation for the Care of Newborn Infants |
| ESPR | European Society for Paediatric Research |
| GLANCE | Global Alliance for Newborn Care |
| IFCDC | Infant and Family-Centred Developmental Care |
| KMC | Kangaroo Mother Care |
| МОМ | Mother's Own Milk |
| NICU | Neonatal Intensive Care Unit |
| NIDCAP | Newborn Individualised Developmental Care and Assessment Program |
| SDGs | Sustainable Development Goals |
| UENPS | Union of European Neonatal & Perinatal Societies |
| UNCRC | United Nations Convention on the Rights of the Child |
| WHO | World Health Organization |



Definition of terms

| Family | In this report, family refers to a newborn's biological and/or social parents, legal guardians, primary caregivers and family members |
|--|---|
| Family-centred care | An approach that places the newborn firmly in the context of the family, acknowledging that the family is the most important and constant influence on the infant's development. At the same time, family-centred care concepts accept that the whole family is affected by what happens to the child |
| Infant and family-centred developmental care | A term for a framework of newborn care that incorporates the concepts of neurodevelopment, neuro-behaviour, parent-infant interaction, parental involvement, breastfeeding promotion, environmental adaptation, and change of hospital systems |
| Special/intensive (newborn) care | Key inpatient care (24/7) for preterm, sick, and low birthweight infants provided in a (higher-level) health facility |
| Low birthweight infant | A newborn who weighs less than 2500 grams at birth irrespective of gestational age |
| Mother's own milk | Milk used from a breastfeeding mother to nourish her own child |
| Newborn | An infant or neonate who is in the first 28 days after birth (the term 'newborn' is predominantly used in this report) |
| COVID-19 pandemic | Also known as coronavirus pandemic, the COVID-19 pandemic is a global outbreak of coronavirus disease in 2019, caused by severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2). On 30 January 2020, the WHO declared this outbreak a Public Health Emergency of International Concern and on 11 March 2020 as a pandemic |
| Parents | Individual biological and/or social parents, legal guardians or primary caregivers of a newborn. In this report, the term also refers to persons who represent views on behalf of parents of particularly preterm, sick or low birthweight newborns |
| Preterm born infant | Infant born before 37 completed weeks of gestation (extremely preterm <28 completed weeks, very preterm 28 to <32 completed weeks, moderate to late preterm 32 to <37 completed weeks) |
| Sick newborn | A newborn requiring medical care |

Parents' voices

"Immediately after birth, the child was taken to a hospital 130 km away, I did not see the child after birth, no one showed it to me, no one could be with me after the caesarean section. When I was registered and wanted to go to the child, the hospital said it was forbidden to visit. I did not see my daughter for 2 months, only a few photos throughout the period, I saw the child for the first time on the day of discharge. That was a nightmare." (Poland)



"It was terrible for my husband not being allowed to see his baby for nearly six weeks. He said he felt totally disconnected from her. I felt the wearing of masks in the unit was inhibiting bonding with my baby. I couldn't kiss her or hold her too close to me as I didn't want her held up against a dirty facemask. Facilities for parents to make a cup of tea and use the toilet were all closed, never felt comfortable in the unit because of this." (Ireland)

"The hospital deprived me of two months and eight days with my child, when he needed me and one cannot do that. He will fill this great wound that I have inside me. To be able to touch him, to be able to see him, to feel me close to him, to be able to get more empowered. They deprived me of my first bath, my first hug, my first kiss. All this was done by many robotic hands and not the warmth of mom or dad. I did not know if this baby they gave me after 2 months was mine or not. Seeing him every day from photos, he had another face (tired distressed, anxious, asleep). If my own child did not have a mark on his face to know that this is him, I would be very worried if I had taken the right child in my arms. It was a tragic period that will never leave my thoughts, it was a pain and a sorrow that will always remain engraved in my mind and soul." (Cyprus)

"A baby needs both parents to develop and to get well. You should ALWAYS be allowed to be with the child. It's crazy what is being done with the psychological health of a young family at the moment!" (Austria)

"Being separated from my partner in the NICU and wearing masks for the first three months of my daughters' life worry me far greater than COVID." (Australia)

"It was so difficult, especially with a toddler at home. It felt like a daily game of Tetris. We generally knew the rules and had a plan as birth approached but then when my uterus ruptured early, it felt like all the Tetris pieces were falling faster and faster and we could barely keep up with putting them in the right place. It was so much to coordinate for on those daily visits without being able to leave our older daughter with other caregivers due to social distancing. It meant that my spouse missed out on almost all those first weeks in NICU." (Canada)

"The differences per hospital were large. We were lucky with the hospital we received care from." (The Netherlands)



"The treatment was really good and I do not feel that the Corona situation affected the quality of care in any way."

(Finland)

"I could see my baby for the first time only one month after his birth. Terrible!!!" (Italy)

"I tested COVID positive and had to deliver the baby at 35 weeks. I could neither see my baby nor hold her. It was the worst three weeks of my life as they took my baby to the NICU and I could only see her once she was discharged after three weeks for the first time." (South Africa)

"My twins received the most outstanding care from the special care unit at the hospital they were birthed. I'm forever grateful for the amazing support and love given to them and to my husband and I." (Australia)

"It should be the right of babies and parents to always be together despite the pandemic, of course with the necessary health checks." (Mexico)

"I could not be the mother I wanted when I was alone with my twins. I felt mentally bad about not being able to practice kangaroo care as much as I wanted. I was deprived of giving the children the best conditions. It was all about survival."

(Sweden)

"After day 20, the COVID restrictions started and it was very aggravating, even my milk decreased, they cut off my contact with my babies and the visitation was limited to only ten minutes. Time was definitely not enough because I had twins. We are special families who are already self-conscious, we were taking a lot of precautions and also taking the hospital's precautions. Precautions are good, but the mother and her children need to be together. Even my mental health was broken. Also, just as we mothers, the fathers have rights. Fathers could not enter the ward and my husband was devastated every day as if we were not happy to bring a new baby into the world, but the crime of bringing a sick baby was created in our brain." (Turkey)

"I had a premature baby two years ago. Compared to that time, I feel I'm connecting less with my baby and us as a family are not bonding together as much." (Portugal)

Parents' voices

"We were only allowed one parent to visit at a time. This made parenting very difficult trying to share what we noticed about our baby and our medical conversations for over 2 and a half months. We also got kicked out of morning rounds about our daughter due to social distancing and we truly believe that kept us in the hospital longer because we weren't a part of the medical conversations. We know our baby best and once they finally talked to us that's when improvements were made but we had to fight to get them to listen." (Canada)

"A very difficult time to have a baby, however, my baby was discharged just as lockdown was starting. I don't think she was really ready to be discharged at the time and we also had to isolate prior to her discharge due to our other daughter having a cough. This was a very tough time but we were glad to get our baby home and she is thankfully doing well now. I feel that the medical staff did do all they could to be supportive in a very uncertain time." (United Kingdom)

"Please ensure that the Ministry of Health allows mothers to reach and touch their babies because mothers need their babies and their babies need their mothers." (Turkey) "It was very isolating and scary to be caring for a preterm baby in the NICU during Covid. I would visit my baby daily but was worried I was bringing the virus home to my family and two other children every day. I do not feel there was adequate support at the hospital for my mental wellbeing during our stay as I was the only parent allowed to see her." (Canada)

Executive summary

Worldwide, the COVID-19 pandemic has created exceptional challenges. Restrictions to stem virus transmission have negatively influenced the provision and quality of healthcare, including infant and family-centred developmental care (IFCDC). Preterm, sick, and low birthweight infants, together with their families, have been severely affected by separation policies with so far unforeseen short- and long-term consequences.

By taking a parent perspective, this research was conducted to explore parents' experiences with regard to the disruptions and restrictions on different elements of IFCDC during the first year of the COVID-19 pandemic. Parents of newborns in need of special/intensive care shared their experiences regarding prenatal care, parental access, infant nutrition and breastfeeding, health communication, and mental health. With the use of an online-survey, which was disseminated in 23 languages, data were collected between August and November 2020. Overall, 2103 parents from 56 countries participated in the survey. The key findings are alarming:

Prenatal care and birth

42% of all participants were not allowed to be accompanied by a support person during prenatal appointments. More than half of the respondents (52%) reported that they were not permitted to have a support person present during birth, leaving them without emotional, informational and practical support.

Presence with the newborn and skin-to-skin care

Overall, one in five (21%) participants answered that no one was ever permitted to be present with the infant receiving special/intensive care. Only 74% of participants indicated that the mother and 56% that the father/partner was allowed to be present with the hospitalised infant. 28% of mothers and 49% of fathers/partners were not at all involved in the care of their infant by medical staff, leaving them without practical experience before discharge.

Infant nutrition and breastfeeding

18% of the respondents reported that they were not at all encouraged to breastfeed the newborn; breastfeeding support was however mostly maintained during the pandemic in many of the included countries and the respective units.

Communication and health information

A third of respondents lacked adequate information on how to protect themselves and the baby from COVID-19 transmission during the hospital stay and at discharge, leaving them without necessary professional advice.

Mental health and suppor

More than 75% of the respondents worried because of the COVID-19 situation during pregnancy and after birth, putting additional stress on the parents in an already challenging situation.

The application of a holistic IFCDC approach urgently needs to be strengthened – worldwide. This is even more important in times of crisis, where restrictions are quickly implemented. The findings of this research have to be acknowledged to end and prevent suffering of vulnerable newborns and their families. IFCDC must be re-installed where it was discontinued, it must be promoted where it was questioned, and it must be protected where it was restricted.

ACTION

FOR ZERO SEPARATION AND INFANT AND FAMILY-CENTERED DEVELOPMENTAL CARE (IFCDC)

Based on the findings of this research initiated by the European Foundation for the Care of Newborn Infants (EFCNI), and under the umbrella of the Global Alliance for Newborn Care (GLANCE), we request policy-makers, for public health experts and healthcare professionals to:



Provide every woman with a safe environment and respectful and supportive care during pregnancy, labour and birth, and allowing support persons to be present during prenatal appointments and birth.



Provide every baby born too soon, too small, or too sick with high-quality care in all settings for the best start in life.



Value, include, and empower parents as key caregivers of their newborns at all times.



Establish a zero separation and family-inclusive policy in hospitals, ensuring parental presence to enable immediate skin-to-skin and Kangaroo Mother Care, and family-infant bonding.



Prioritise mother's own milk and encourage breastfeeding when possible, emphasising the benefits of adequate infant nutrition for all newborns.



Ensure adequate provision of health information and continuous and respectful communication between healthcare professionals and parents.



Offer and provide access to mental health support to parents and families in need.



Ensure a smooth and holistic application of IFCDC in general and in times of crisis.

ZERO SEPARATION. TOGETHER FOR BETTER CARE!



Infant and family-centred developmental care (IFCDC) in times of COVID-19

In the last decade, many achievements could be celebrated in the field of maternal and newborn health. However, while important improvements have resulted in reduced maternal and infant mortality rates and better health outcomes of newborns, progress with regards to preterm, sick, and low birthweight infants has been particularly slow.^{1,2} Across the globe, one in ten infants is born preterm every year, with increasing rates in several countries.³ Preterm birth, together with low birthweight, infections, and birth trauma, remain to be the leading cause of neonatal death.^{4–6} Progress has furthermore been uneven across countries and regions, leaving in particular those behind that are facing poor and under-resourced settings.²

The COVID-19 pandemic has created additional challenges and disrupted healthcare systems all across the globe with substantial implications for the provision of infant- and family-centred developmental care (IFCDC).^{7–10} The observed shortages in the provision of maternal and newborn care have severe consequences for newborns and their families,¹¹ and constitute a real threat to the achievement of the Sustainable Development Goals and the 2030 Development Agenda.⁴

In contrast to international agreements, like the United Nations Convention on the Rights of the Child (UNCRC) or the European Association for Children in Hospital (EACH), which emphasise the right of children to be close to their parents, separation policies have been implemented in many neonatal units worldwide – already before the current COVID-19 pandemic – and increasingly ever since in order to reduce infection rates.^{12–14}

While acknowledging the need to tackle the pandemic, some measures, such as the separation of vulnerable newborns from their parents, have severe short- and long-term consequences for infants and their families.¹⁵⁻¹⁸ The negative implications of implemented restrictions on elements of IFCDC are multi-fold, reportedly affecting amongst others skin-to-skin care and Kangaroo Mother Care (KMC), initiation of breastfeeding, family bonding, and mental health.^{13,14,19–21} Furthermore, also healthcare professionals had and still have to cope with challenging working conditions, such as staff shortages, lack of protective hygiene equipment e.g. face masks and gloves, missing guidelines and support, which ultimately lead to increased anxiety and stress levels, and put additional pressure on already challenged care provision.^{22,23}

The severe consequences of restrictions and implemented separation policies in neonatal care, together with a lack of scientific evidence on how to respond to crisis situations, have resulted in the initiation of this research. Focusing exclusively on parents' perceptions, this research aimed at exploring their unique experiences regarding care provision and the impact of implemented restrictions around the world on key characteristics of IFCDC – in particular during the ongoing pandemic. Parents play the key role in the care of their newborn and listening to them and their experiences is crucial to provide adequate and respectful care in the current but also future emergency situations, and to finally enable the best start in life for every newborn.





This report is based on a multi-lingual online-survey which targeted parents of preterm, sick or low birthweight infants born during the first year of the COVID-19 pandemic (as of 1of December 2019) and who were receiving special or intensive care. Throughout the report, the term "parent" covers biological and/or social parents, as well as legal guardians of preterm, sick, and low birthweight infants. The participants of the study had the opportunity to self-define as either "mother", "father", or "other parent". The study was performed in line with the Checklist for Reporting Results of Internet E-Surveys (CHERRIES). 24

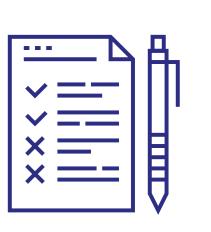
The questionnaire was developed by the Scientific Affairs Department of EFCNI in close collaboration with the members of the COVID-19 Zero Separation Collaborative Group, which is an interdisciplinary group consisting of experts in the respective medical field and parent representatives. The questionnaire consisted of 52 questions, with pre-defined answers and single or multiple response answer options, and one open question. Enquired were characteristics of core elements of IFCDC covering – next to background and COVID-19 related questions – experiences with regard to prenatal care, presence with the newborn and skin-to-skin care, breastfeeding and infant nutrition, health communication, and mental health and support.

The set of questions was critically reviewed and pre-tested among parents (n=8) to ensure a parent-friendly wording and appropriateness of included content. Parent representatives from the EFCNI network translated the survey into 23 languages (Bulgarian, Chinese, Czech, Dutch, English, Finnish, French, German, Greek, Hungarian, Italian, Japanese, Macedonian, Norwegian, Polish, Portuguese, Romanian, Russian, Slovakian, Swedish, Spanish, Turkish and Ukrainian). Native medical experts reviewed every single translation for correctness.

Parents across the globe were invited to participate through social media postings, newsletter announcements, and website outreach by EFCNI and GLANCE. In addition, national parent organisations and the collaborating professional healthcare societies (COINN, ESPR, NIDCAP, UENPS) supported the promotion of the survey link in their own networks. A communication toolkit was provided by EFCNI for this purpose.

Data collection occurred between August and November 2020 using an online survey tool (SurveyMonkey®). Data were analysed following an exploratory approach with descriptive statistics (relative frequencies and percentages (n (%)); multiple response questions were analysed as the sum of answers per option), and using SPSS software (IBM SPSS Statistics for Windows, version 27.0, IBM Corp, Armonk, New York). For the illustration of the results, the freeware Datawrapper and Microsoft Excel 2019 were used. The open question was analysed qualitatively; results are presented with direct quotes throughout the report.

Data were collected, processed, and stored in accordance with the General Data Protection Regulation and the Declaration of Helsinki. The respondents of this study were informed in an introductory text about the survey, data collection process, and privacy. They were made aware that some of the questions might cause distressing reactions considering their very personal experience. By checking a confirmation box, informed consent was confirmed. No financial or other incentives were offered. Data collection occurred anonymously. All respondents had the opportunity to stop participation at any time. The Ethics Committee of Maastricht UMC+, the Netherlands, officially waived the need for ethics approval for this study (METC 2020-1336).







In the following, the results of the global survey among parents of hospitalised infants born during the first year of the COVID-19 pandemic are presented. This results section is structured into different topic areas, which correspond to core elements of IFCDC. Thereby, the total and regional results which have previously been published as scientific research by Kostenzer et al.¹⁰ are firstly summarised, covering data from all 56 countries included in the survey (*Figure 1*; *Supplementary Table S1*). Subsequently, 30 countries (with at least 20 respondents per country) were included in the country-specific overview.



Figure 1. Countries participating in the survey (according to Kostenzer et. al (2021))¹⁰

3.1 Key findings at a glance

PRENATAL CARE AND BIRTH

42%

of all participants were not allowed to be accompanied by a support person during prenatal appointments.

More than half of the respondents reported that they were not permitted

52%

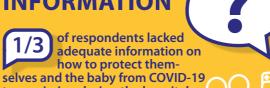
to have a support person present during birth, leaving them without emotional, informational and practical support.

INFANT NUTRITION AND BREASTFEEDING



18% of the respondents reported that they were not at all encouraged to breastfeed the newborn; breastfeeding support was however mostly maintained during the pandemic in many of the included countries and the respective units.

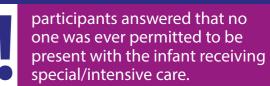
COMMUNICATION AND HEALTH INFORMATION



transmission during the hospital stay and at discharge, leaving them without necessary professional advice.

PRESENCE WITH THE NEWBORN AND SKIN-TO-SKIN CARE

one in five (21%)



Only **74%** of participants indicated that the mother and **56%** that the father/partner was allowed to be present with the hospitalised infant.

28% of mothers and 49% of fathers/ partners were not at all involved in the care of their infant by medical staff, leaving them without practical experience before discharge.





MOTHERS

FATHERS

WERE NOT AT ALL INVOLVED IN THE CARE OF THEIR INFANT BY MEDICAL STAFF

MENTAL HEALTH AND SUPPORT



More than 75% of the respondents worried because of the COVID-19 situation during pregnancy and after birth, putting additional stress on the parents in an already challenging situation.

Zero separation. Together for better care!

3.2 Participants and COVID-19 related characteristics

Overall, 2103 participants from 56 different countries participated in the survey. While 2978 parents initially started the questionnaire, few declined participation (n=23), and 852 did not provide necessary details on or did not meet inclusion criteria (*Figure 2*).

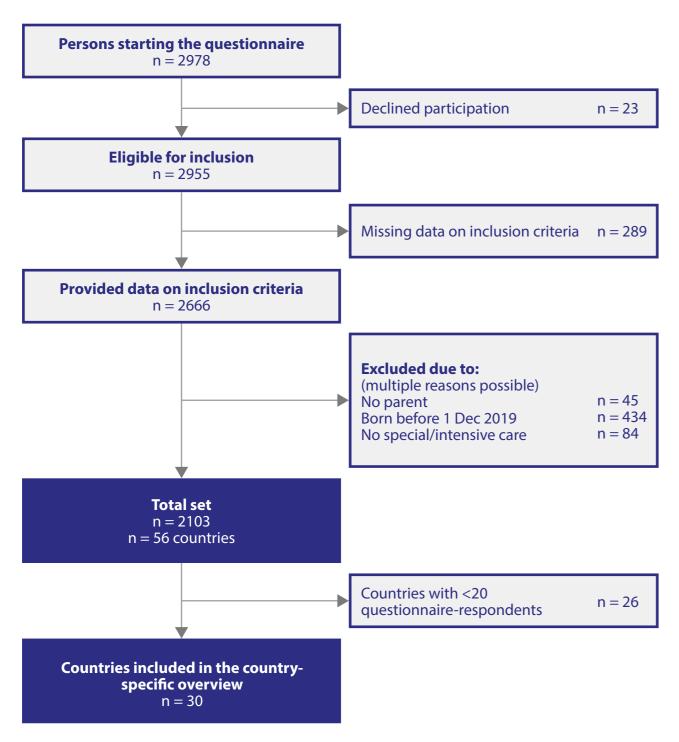


Figure 2. Flow-chart of questionnaire respondents (Kostenzer et al. (2021))¹⁰

As shown in *Table G1*, more than half of the respondents were between 30 and 39 years old. Caesarean section was the most common birth mode (68%) with only 5% of the infants being born at term. Hospital stays varied and must be interpreted in light of the point of participation, as some parents answered to the questionnaire while their newborn was still hospitalised. Less than 5% of either the participating parents, their newborn or partner have tested COVID-19 positive.

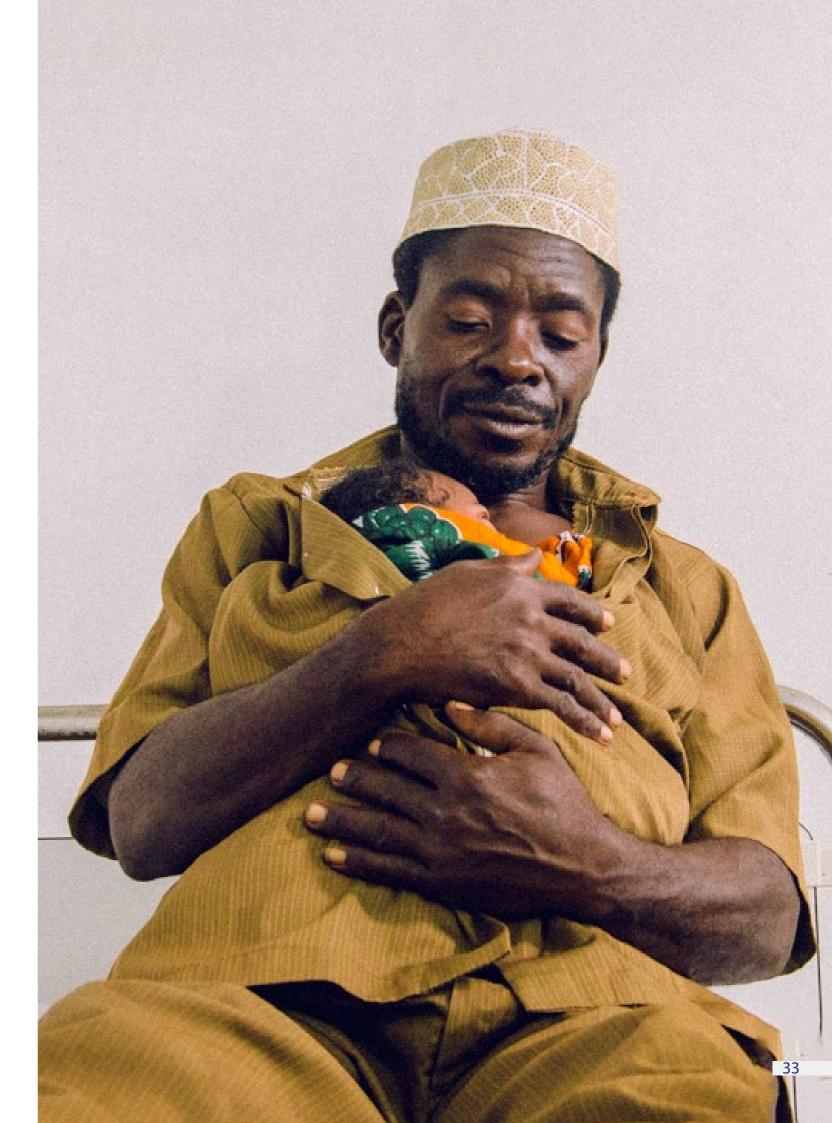


Table G1. Participants and COVID-19 related characteristics

| | Total | Africa | Americas | Europe | Western Pacific |
|--|------------|----------|-----------|------------|--------------------|
| Age of respondent (years) | n = 2097 | n = 25 | n = 247 | n = 1656 | n = 161 |
| <20 | 13 (1%) | 0 (0%) | 2 (1%) | 9 (1%) | 2 (1%) |
| 20–29 | 748 (36%) | 8 (32%) | 88 (36%) | 603 (36%) | 45 (28%) |
| 30–39 | 1200 (57%) | 14 (56%) | 132 (53%) | 949 (57%) | 102 (63%) |
| >40 | 17 (1%) | 3 (12%) | 25 (10%) | 95 (6%) | 12 (7%) |
| Relation to the child | n = 2103 | n = 25 | n = 248 | n = 1658 | n = 162 |
| Mother | 2004 (95%) | 23 (92%) | 240 (97%) | 1587 (96%) | 144 (89%) |
| Father | 99 (5%) | 2 (8%) | 8 (3%) | 71 (4%) | 18 (11%) |
| Gestational age at birth (weeks) | n = 2023 | n = 23 | n = 240 | n = 1602 | n = 153 |
| Early preterm: <28 | 381 (24%) | 5 (22%) | 49 (20%) | 374 (23%) | 50 (33%) |
| Very preterm: 28–<32 | 664 (33%) | 7 (30%) | 83 (35%) | 524 (33%) | 48 (31%) |
| Moderate to late preterm: 32–<37 | 769 (38%) | 11 (48%) | 99 (41%) | 614 (38%) | 45 (29%) |
| Term: 37–42 | 109 (5%) | 0 (0%) | 9 (4%) | 90 (6%) | 10 (7%) |
| Multiple pregnancy | n = 2030 | n = 23 | n = 239 | n = 1607 | n = 154 |
| Yes | 309 (15%) | 2 (9%) | 31 (13%) | 241 (15%) | 33 (21%) |
| No | 1721 (85%) | 21 (91%) | 208 (87%) | 1366 (85%) | 121 (79%) |
| Birth mode | n = 2027 | n = 23 | n = 240 | n = 1605 | n = 153 |
| Vaginal birth | 632 (31%) | 3 (13%) | 69 (29%) | 504 (31%) | 53 (35%) |
| C-section | 1381 (68%) | 19 (83%) | 168 (70%) | 1093 (68%) | 98 (64%) |
| Both (e.g. in case of multiple pregnancy) | 14 (1%) | 1 (4%) | 3 (1%) | 8 (0%) | 2 (1%) |
| Birth weight of the baby (grams) | n = 2028 | n = 23 | n = 240 | n = 1604 | n = 154 |
| <1000 | 514 (25%) | 5 (22%) | 54 (23%) | 405 (25%) | 48 (31%) |
| 1000–1500 | 621 (31%) | 6 (26%) | 80 (33%) | 481 (30%) | 51 (33%) |
| >1500–2500 | 698 (34%) | 6 (26%) | 89 (37%) | 562 (35%) | 39 (25%) |
| >2500 | 193 (10%) | 6 (26%) | 17 (7%) | 154 (10%) | 16 (10%) |
| Don't know the birth weight | 2 (0%) | 0 (0%) | 0 (0%) | 2 (0%) | 0 (0%) |
| Duration of special/intensive care (weeks) | n = 2029 | n = 23 | n = 241 | n = 1604 | n = 154 |
| <1 | 172 (9%) | 1 (4%) | 27 (11%) | 135 (8%) | 9 (6%) |
| 1–3 | 474 (23%) | 7 (30%) | 50 (21%) | 386 (24%) | 31 (20%) |
| >3-5 | 454 (22%) | 4 (17%) | 44 (18%) | 364 (23%) | 40 (26%) |
| >5 | 929 (46%) | 11 (48%) | 120 (50%) | 719 (45%) | 74 (48%) |
| Different countries and regions have been addressing the threat of COV-ID-19 in different ways. Which of the following best describes the situation in your country/region around the time of your baby's birth? | n = 1963 | n = 22 | n = 235 | n = 1555 | n = 150 |
| No major concern | 83 (4%) | 1 (5%) | 11 (5%) | 57 (4%) | 14 (9%) |
| Precautions | 227 (12%) | 1 (5%) | 23 (10%) | 159 (10%) | 44 (29%) |
| Social distancing | 550 (28%) | 4 (18%) | 44 (19%) | 468 (30%) | 34 (23%) |
| Lockdown | 869 (44%) | 10 (46%) | 124 (53%) | 681 (44%) | 53 (35%) |
| Quarantine | 234 (12%) | 6 (27%) | 33 (14%) | 190 (12%) | 5 (3%) |
| Have you tested positive for COVID-19? | n = 1990 | n = 22 | n = 238 | n = 1570 | n = 153 |
| Yes No | 55 (3%) | 1 (5%) | 14 (6%) | 39 (2%) | 1 (1%) |

Note: percentages may not total 100% due to rounding

Table G1. Participants and COVID-19 related characteristics (continued)

| | Total | Africa | Americas | Europe | Western Pacific |
|--|------------|-----------|-----------|------------|--------------------|
| Has your partner tested positive for COVID-19? | n = 1993 | n = 22 | n = 238 | n = 1574 | n = 152 |
| Yes | 50 (3%) | 0 (0%) | 17 (7%) | 32 (2%) | 1 (1%) |
| No | 1907 (96%) | 22 (100%) | 212 (89%) | 1516 (96%) | 150 (99%) |
| Don't know | 36 (2%) | 0 (0%) | 9 (4%) | 26 (2%) | 1 (1%) |
| Has your baby tested positive for | n = 1993 | n = 22 | n = 238 | n = 1573 | n = 153 |
| COVID-19? | | | | | |
| Yes | 11 (1%) | 0 (0%) | 3 (1%) | 7 (0%) | 1 (1%) |
| No | 1901 (95%) | 22 (100%) | 227 (95%) | 1497 (95%) | 148 (97%) |
| Don't know | 81 (4%) | 0 (0%) | 8 (3%) | 69 (4%) | 4 (3%) |

Note: percentages may not total 100% due to rounding

3.3 Prenatal care and birth

The pandemic influenced the timing and frequency of prenatal care appointments. One-third of the respondents indicated that fewer pregnancy-related appointments took place than usual, and in 6% of the cases, even no appointments took place. Only around half of the respondents (49%) indicated, that COVID-19 related measures did not affect the timing of pregnancy-related appointments. Furthermore, also the option to have support persons present in the perinatal phase was strongly influenced.¹⁰



For 42% of the respondents, it was not possible to bring their partner or another support person to pregnancy-related appointments, and for slightly more than half of the respondents (52%), it was not permitted to have another person present during birth.¹⁰



For persons who were permitted to have a companion present during birth, 76% were allowed to stay for the whole duration of labour, whereas 24% could only be present for a part of it (*Table G2*).

Table G2. Prenatal care and birth

| | Total | Africa | Americas | Europe | Western Pacific |
|--|-----------|----------|----------|------------|--------------------|
| How was the timing of pregnan- cy-related appointments affected, if at all, by COVID-19? | n = 1913 | n = 22 | n = 224 | n = 1513 | n = 148 |
| It was done as usual | 937 (49%) | 11 (50%) | 95 (42%) | 746 (49%) | 81 (55%) |
| No appointments took place | 105 (6%) | 3 (14%) | 21 (9%) | 78 (5%) | 2 (1%) |
| Fewer appointments took place | 634 (33%) | 6 (27%) | 83 (37%) | 492 (33%) | 53 (36%) |
| Other | 237 (12%) | 2 (9%) | 25 (11%) | 197 (13%)) | 12 (8%) |
| Was another person permitted to accompany you to pregnancy-related appointments during the COVID-19 phase? | n = 1911 | n = 22 | n = 224 | n = 1511 | n = 148 |
| Yes | 396 (21%) | 5 (23%) | 59 (26%) | 286 (19%) | 44 (30%) |
| Not to all appointments | 531 (28%) | 3 (14%) | 55 (25%) | 417 (28%) | 56 (38%) |
| No, never | 793 (42%) | 13 (59%) | 87 (39%) | 649 (43%) | 41 (28%) |
| Don't know/NA | 191 (9%) | 1 (5%) | 23 (10%) | 159 (11%) | 7 (5%) |

Note: percentages may not total 100% due to rounding

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Table G2. Prenatal care and birth (continued)

| | Total | Africa | Americas | Europe | Western Pacific |
|---|-----------|-----------|-----------|-----------|--------------------|
| Were you permitted to have another person present with you during birth (e.g. partner)? | n = 1914 | n = 22 | n = 225 | n = 1512 | n = 149 |
| Yes | 926 (48%) | 14 (64%) | 116 (52%) | 689 (46%) | 103 (69%) |
| No | 988 (52%) | 8 (36%) | 109 (48%) | 823 (54%) | 103 (09%) |
| For how long was this person permitted to stay with you? | n = 975 | n = 14 | n = 123 | n = 733 | n = 105 |
| For the entire labour | 741 (76%) | 14 (100%) | 93 (76%) | 545 (74%) | 89 (85%) |
| For a part of it (please elaborate): | 234 (24%) | 0 (0%) | 30 (24%) | 188 (26%) | 16 (15%) |

Note: percentages may not total 100% due to rounding

3.4 Presence with the newborn and skin-to-skin care

Implications for being present with the newborn were identified with more than 80% of the participants experiencing severe access restrictions (*Table G3*). Overall, in 63% of the cases, no more than one person was allowed to be present with the newborn at the same time. Both mothers and fathers/partners were therefore denied access to their infant receiving special/intensive care to varying degrees. Mothers were allowed to be present to 74%, whereas only 56% of the fathers/partners could be with their hospitalised child. In one out of five cases, nobody was allowed to be with the newborn (21%).¹⁰

Furthermore, siblings and other family members were only rarely allowed to be present (3%, 2% respectively), with often very stressful and traumatic experiences for the whole family.

"

All the time everyone
was talking about the
baby, baby, baby. But
Corona forced me into a
situation where I had to abandon
my own husband and even my
own 3-year-old daughter for 5 weeks!
I only met my other daughter in the car
in the parking lot. She was under 3 years old
and really didn't understand. I was in the ward,
before giving birth and the rest of the time with the
baby. My firstborn must have been traumatised
when she had never had a day without her
mother before.

(Finland)

and didn't see our b 3 weeks. This made

My husband didn't see our baby for almost 13 weeks. This made it very difficult for him as he felt he was excluded and not an important part of his first baby's life. As a mother, I then worried about the wellbeing of both my baby and my husband. This added stress to an already unimaginable situation.

(Ireland)

Adding to this, also the duration of parental presence was affected. Only half of the respondents (55%) answered that they could be present with the infant all the time or at least multiple times per day. Unlimited access was possible for 41% of the participants, and 30% could only be present with the newborn for maximum one hour. For about half of the respondents (52%), also no technical alternatives to being present with the infant were offered, such as e.g. photos or videos.¹⁰

Restrictions with regard to parental presence also impacted the provision of skin-to-skin care (including KMC) and thus parent-infant bonding. While 46% of the participants stated that they were able to have skin-to-skin contact during the first week, only 10% indicated that it was initiated immediately after birth. Also, 21% of the respondents answered that skin-to-skin contact was not initiated at all during hospitalisation. Restrictions could furthermore be observed with regards to the frequency of contact. Unrestricted skin-to-skin contact was only reported by 30% of parents. Touching the infant in the bed or incubator was possible for 79% of the participants, however, only 53% of them could do so as often as desired.¹⁰



The majority of the parents felt that the implemented restrictions made it more difficult to be present (71%) or even interactive (62%) with the newborn. While 28% of the respondents indicated that they were not involved in the care of their newborn by medical staff, numbers for their partners were even higher (49%; *Table G3*).¹⁰

Table G3. Presence with the newborn and skin-to-skin care

| | Total | Africa | Americas | Europe | Western Pacific |
|--|-------------|-----------|------------|-------------|--------------------|
| Do you know if the COVID-19 situation affected the facility policy around your ability to be present with the baby receiving special/intensive care? | n = 1813 | n = 22 | n = 219 | n = 1421 | n = 147 |
| There were no changes | 145 (8%) | 1 (5%) | 10 (5%) | 118 (8%) | 16 (11%) |
| Restrictions were implemented | 1511 (83%) | 21 (95%) | 196 (89%) | 1177 (83%) | 113 (77%) |
| I don't know if there were changes | 157 (9%) | 0 (0%) | 13 (6%) | 126 (9%) | 18 (12%) |
| Who was allowed to be present with your baby receiving special/intensive care? (multiple answers possible) | n = 1814 | n = 22 | n = 219 | n = 1422 | n = 147 |
| Sum of multiple answers | 2856 (157%) | 30 (136%) | 355 (162%) | 2206 (155%) | 260 (172%) |
| Mother | 1343 (74%) | 16 (73%) | 170 (78%) | 1048 (74%) | 107 (73%) |
| Father/partner | 1020 (56%) | 12 (55%) | 148 (68%) | 757 (53%) | 102 (69%) |
| Sibling/s | 52 (3%) | 0 (0%) | 3 (1%) | 41 (3%) | 8 (5%) |
| Other family members | 42 (2%) | 0 (0%) | 5 (2%) | 28 (2%) | 9 (6%) |
| Friends | 13 (1%) | 0 (0%) | 1 (0%) | 12 (1%) | 0 (0%) |
| No one | 376 (21%) | 2 (9%) | 27 (12%) | 318 (22%) | 27 (18%) |
| I don't know | 10 (1%) | 0 (0%) | 1 (0%) | 2 (0%) | 7 (5%) |

Note: percentages may not total 100% due to rounding

38

Table G3. Presence with the newborn and skin-to-skin care (continued)

| | Total | Africa | Americas | Europe | Western Pacific |
|---|------------------------|--------------------|----------------------|------------------------|----------------------|
| Could more than one person be present with the baby at the same time? | n = 1813 | n = 22 | n = 219 | n = 1421 | n = 147 |
| Yes | 664 (32%) | 4 (18%) | 46 (21%) | 532 (37%) | 81 (55%) |
| No | 1149 (63%) | 18 (82%) | 173 (79%) | 889 (63%) | 66 (45%) |
| How often were you allowed to see your baby receiving special/intensive care? | n = 1812 | n = 22 | n = 217 | n = 1422 | n = 147 |
| All the time, (24/7) | 668 (37%) | 5 (23%) | 66 (30%) | 522 (37%) | 75 (51%) |
| Multiple times per day | 326 (18%) | 3 (14%) | 37 (17%) | 272 (19%) | 13 (9%) |
| Once per day | 351 (19%) | 10 (45%) | 84 (39%) | 251 (18%) | 5 (3%) |
| Multiple times per week | 76 (4%) | 2 (9%) | 5 (2%) | 66 (5%) | 3 (2%) |
| Once per week | 66 (4%) | 1 (5%) | 5 (2%) | 58 (4%) | 2 (1%) |
| Less than once per week Never | 57 (3%) 268 (15%) | 0 (0%) 1 (5%) | 5 (2%) 15 (7%) | 46 (3%) 207 (15%) | 5 (3%) 44 (30%) |
| How long were you allowed to see your | n = 1810 | n = 22 | n = 218 | n = 1419 | n = 147 |
| baby per visit? | | | | | |
| Up to an hour | 551 (30%) | 6 (27%) | 84 (39%) | 455 (32%) | 5 (3%) |
| More than one hour, up to three hours | 133 (7%) | 5 (23%) | 16 (7%) | 101 (7%) | 9 (6%) |
| More than three hours, but not unlimited Unlimited | 122 (7%) 746 (41%) | 5 (23%) | 21 (10%) 84 (39%) | 85 (6%) | 11 (7%) 77 (52%) |
| Not at all | 258 (14%) | 5 (23%) 1 (5%) | 13 (6%) | 580 (41%) 198 (14%) | 45 (31%) |
| Do you feel that the measures that were | 238 (1470) | 1 (370) | 13 (070) | 190 (1470) | 45 (51 /0) |
| implemented due to COVID-19 (e.g. restrictions by hospital management) made it more difficult for you to be present with your baby? | n = 1812 | n = 22 | n = 218 | n = 1422 | n = 146 |
| Yes | 1294 (71%) | 20 (91%) | 174 (80%) | 998 (70%) | 99 (68%) |
| No, not more difficult | 372 (21%) | 2 (9%) | 34 (16%) | 307 (22%) | 28 (19%) |
| No, there were no restrictive measures in place | 100 (6%) | 0 (0%) | 7 (3%) | 85 (6%) | 8 (5%) |
| Don't know | 46 (3%) | 0 (0%) | 3 (1%) | 32 (2%) | 11 (8%) |
| When was skin-to-skin contact with your baby and one of the parents initiated (e.g. holding the baby on the chest, kangaroo mother care)? | n = 1910 | n = 22 | n = 225 | n = 1510 | n = 148 |
| Immediately after birth | 183 (10%) | 0 (0%) | 21 (9%) | 145 (10%) | 17 (11%) |
| On the first day | 220 (12%) | 0 (0%) | 10 (4%) | 190 (13%) | 20 (14%) |
| After the first day but during the first week | 451 (24%) 448 (24%) | 4 (18%) 8 (36%) | 52 (23%) 72 (32%) | 354 (23%) 344 (23%) | 39 (26%) 23 (16%) |
| After the first week | | | | | |
| Not so far (If you are still in the hospital with your baby) | 204 (11%) | 2 (9%) | 15 (7%) | 141 (9%) | 46 (31%) |
| Not during the time in the hospital (if you are already at home with your baby) | 404 (21%) | 8 (36%) | 55 (24%) | 336 (22%) | 3 (2%) |
| How often were you permitted to have skin-to-skin contact (kangaroo mother care) with your baby? | n = 1909 | n = 22 | n = 223 | n = 1511 | n = 148 |
| As often as I wanted | 578 (30%) | 7 (32%) | 62 (28%) | 471 (31%) | 36 (24%) |
| At least once per day | 518 (27%) | 5 (23%) | 81 (36%) | 384 (25%) | 47 (32%) |
| At least once per week | 124 (7%) | 1 (5%) | 19 (9%) | 93 (6%) | 11 (7%) |
| Less than once per week | 166 (9%) | 2 (9%) | 21 (9%) | 139 (9%) | 4 (3%) |
| Not so far | 523 (27%) | 7 (32%) | 40 (18%) | 424 (28%) | 50 (34%) |
| Did medical/nursing staff involve you in the care of your baby (e.g. nappy changing, feeding, temperature taking)? | n = 1810 | n = 22 | n = 219 | n = 1419 | n = 146 |
| Yes | 912 (50%) | 11 (50%) | 93 (42%) | 731 (52%) | 76 (52%) |
| No, not more difficult | 391 (22%) | 9 (41%) | 74 (34%) | 282 (20%) | 25 (17%) |
| No, there were no restrictive measures in place | 497 (28%) | 2 (9%) | 52 (24%) | 401 (28%) | 41 (28%) |
| Don't know | 10 (1%) | 0 (0%) | 0 (0%) | 5 (0%) | 4 (3%) |

Note: percentages may not total 100% due to rounding

Table G3. Presence with the newborn and skin-to-skin care (continued)

| | Total | Africa | Americas | Europe | Western Pacific |
|---|---|--|---|---|--|
| Did medical/nursing staff involve your partner in the care of your baby? | n = 1812 | n = 22 | n = 219 | n = 1421 | n = 146 |
| Yes, to a high degree Yes, to some degree No, not at all Don't know I don't have a partner | 573 (32%) 311 (17%) 886 (49%) 24 (1%) 18 (1%) | 5 (23%) 6 (27%) 11 (50%) 0 (0%) 0 (0%) | 58 (26%) 59 (27%) 96 (44%) 5 (2%) 1 (0%) | 452 (32%) 212 (15%) 729 (51%) 14 (1%) 14 (1%) | 57 (39%) 34 (23%) 47 (32%) 5 (3%) 3 (2%) |
| Were you permitted to touch your baby in the incubator or bed? | n = 1916 | n = 22 | n = 226 | n = 1515 | n = 148 |
| Yes No | 1509 (79%) 407 (21%) | 18 (82%) 4 (18%) | 197 (87%) 29 (13%) | 1191 (79%) 324 (21%) | 99 (67%) 49 (33%) |
| Were you permitted to touch your baby in the incubator or bed? | n = 1916 | n = 22 | n = 226 | n = 1515 | n = 148 |
| Yes No | 1509 (79%) 407 (21%) | 18 (82%) 4 (18%) | 197 (87%) 29 (13%) | 1191 (79%) 324 (21%) | 99 (67%) 49 (33%) |
| How often were you permitted to touch your baby in the incubator or bed? | n = 1913 | n = 22 | n = 226 | n = 1512 | n = 148 |
| As often as I wanted At least once per day At least once per week Less than once per week Not so far | 1012 (53%) 372 (19%) 75 (4%) 114 (6%) 340 (18%) | 10 (45%) 7 (32%) 1 (5%) 2 (9%) 2 (9%) | 116 (51%) 69 (31%) 9 (4%) 11 (5%) 21 (9%) | 802 (53%) 282 (19%) 62 (4%) 98 (6%) 268 (18%) | 81 (55%) 14 (9%) 3 (2%) 2 (1%) 48 (32%) |
| Which other options of being present were provided with your baby receiving special/intensive care? (multiple answers possible) | n = 1796 | n = 22 | n = 218 | n = 1408 | n = 144 |
| Sum of multiple answers | 2136 (119%) | 28 (127%) | 256 (117%) | 1689 (120%) | 157 (109%) |
| Photos Livestream Recorded video | 598 (33%) 139 (8%) 169 (9%) | 6 (27%) 1 (5%) 3 (14%) | 53 (24%) 13 (6%) 16 (7%) | 509 (36%) 114 (8%) 145 (10%) | 28 (19%) 10 (7%) 4 (3%) |
| Video calls None Other | 125 (7%) 932 (52%) 173 (10%) | 2 (9%) 16 (73%) 0 (0%) | 23 (11%) 134 (61%) 17 (8%) | 91 (6%) 691 (49%) 139 (10%) | 8 (6%) 90 (63%) 17 (12%) |

Note: percentages may not total 100% due to rounding

3.5 Infant nutrition and breastfeeding

This research indicated that medical and nursing staff highly or somewhat encouraged the initiation of breastfeeding as reported by 77% (*Table G4*). More than 85% of the participants' newborns were either exclusively or at least partly breastfed with the mother's own expressed or pumped milk during the first weeks after birth.¹⁰

The initiation of breastfeeding, however, was often challenging for the participating mothers, and infant formula was sometimes prioritised for different reasons, as the feedback provided by some participants shows.





From the findings of this study, breastfeeding and the provision of mother's own milk either took place on the first day or during the first week after birth. A large majority of respondents (over 70%) was allowed to bring expressed milk from home (*Table G4*).¹⁰

Table G4. Infant nutrition and breastfeeding

| | Total | Africa | Americas | Europe | Western Pacific |
|--|------------|----------|-----------|------------|--------------------|
| Was initiation of breastfeeding encouraged by medical/nursing staff? | n = 1880 | n = 22 | n = 224 | n = 1483 | n = 146 |
| Yes, highly encouraged | 998 (52%) | 12 (55%) | 129 (58%) | 726 (49%) | 129 (88%) |
| Yes, somewhat encouraged | 471 (25%) | 5 (23%) | 63 (28%) | 392 (26%) | 10 (7%) |
| No, not encouraged at all | 331 (18%) | 5 (23%) | 29 (13%) | 293 (20%) | 2 (1%) |
| Don't know | 80 (4%) | 0 (0%) | 3 (1%) | 72 (5%) | 5 (3%) |
| Was your baby breastfed or provided with mother's own pumped/expressed breastmilk in the first weeks after birth? | n = 1879 | n = 22 | n = 224 | n = 1483 | n = 145 |
| Yes, exclusively | 924 (49%) | 13 (59%) | 90 (40%) | 720 (49%) | 98 (68%) |
| Yes, partly | 750 (40%) | 8 (36%) | 108 (48%) | 590 (40%) | 43 (30%) |
| No, not at all | 197 (11%) | 1 (5%) | 25 (11%) | 166 (11%) | 4 (3%) |
| Don't know | 8 (0%) | 0 (0%) | 1 (0%) | 7 (0%) | 0 (0%) |
| When did the initiation of breast- feeding or provision of mother's own pumped/expressed breastmilk take place? | n = 1881 | n = 22 | n = 224 | n = 1484 | n = 146 |
| Not applicable; baby was not breastfed | 160 (9%) | 2 (9%) | 18 (8%) | 136 (9%) | 3 (2%) |
| On the first day | 626 (33%) | 10 (45%) | 54 (24%) | 502 (34%) | 59 (40%) |
| After the first day but during the first week | 756 (40%) | 8 (36%) | 90 (40%) | 590 (40%) | 67 (46%) |
| After the first week | 280 (15%) | 1 (5%) | 59 (26%) | 206 (14%) | 12 (8%) |
| Don't know | 59 (3%) | 1 (5%) | 3 (1%) | 50 (3%) | 5 (3%) |
| Were you allowed to bring expressed milk from home to the unit? | n = 1879 | n = 22 | n = 224 | n = 1482 | n = 146 |
| Not applicable; baby was not breastfed | 124 (7%) | 0 (0%) | 9 (4%) | 112 (8%) | 2 (1%) |
| Yes | 1327 (71%) | 19 (86%) | 132 (59%) | 1035 (70%) | 137 (94%) |
| No, the milk had to be expressed at the hospital | 287 (15%) | 3 (14%) | 73 (33%) | 208 (14%) | 3 (2%) |
| No, other | 141 (8%) | 0 (0%) | 10 (4%) | 127 (9%) | 4 (3%) |

Note: percentages may not total 100% due to rounding

3.6 Communication and health information

Overall, 90% of all respondents indicated "to a high" or "to some degree" that they have received adequate general health information about their newborn. Almost half of the parents were informed at least once per day and almost 70% of the participants were informed about how to protect themselves and their newborn from COVID-19 transmission during the hospital stay. However, 18% of the parents were lacking information and did not feel adequately informed, and 9% did not even receive any kind of information (*Table G5*).¹⁰



When the infant was being discharged from the hospital, 40% of the parents stated that they had not received any or no adequate information regarding COVID-19 protective measures.



Table G5. Communication and health information

| Communication | Total | Africa | Americas | Europe | Western Pacific |
|--|-----------|----------|----------|-----------|--------------------|
| Do you feel you received or are receiving adequate general health information about your baby during the hospital stay? | n = 1790 | n = 21 | n = 212 | n = 1408 | n = 145 |
| Yes, to a high degree | 866 (48%) | 8 (38%) | 94 (44%) | 682 (48%) | 80 (55%) |
| Yes, to some degree | 750 (42%) | 11 (52%) | 93 (44%) | 593 (42%) | 51 (35%) |
| No, not at all | 142 (8%) | 2 (10%) | 19 (9%) | 113 (8%) | 8 (6%) |
| Don't know | 14 (1%) | 0 (0%) | 2 (1%) | 11 (1%) | 1 (1%) |
| I didn't receive any information | 18 (1%) | 0 (0%) | 4 (2%) | 9 (1%) | 5 (3%) |
| Do you feel you received or are receiving adequate information about how to protect yourself and your baby from COVID-19 transmission while your baby received or is receiving special/intensive care? | n = 1789 | n = 21 | n = 212 | n = 1406 | n = 146 |
| Vos to a high dograp | 575 (32%) | 10 (48%) | 64 (30%) | 440 (31%) | 60 (41%) |
| Yes, to a high degree Yes, to some degree | 662 (37%) | 6 (29%) | 86 (41%) | 515 (37%) | 55 (38%) |
| No, not at all | 322 (18%) | 5 (24%) | 39 (18%) | 268 (19%) | 9 (6%) |
| Don't know | 73 (4%) | 0 (0%) | 6 (3%) | 59 (4%) | 7 (5%) |
| DOITENIOW | 157 (9%) | 0 (0%) | 17 (8%) | 124 (9%) | 15 (10%) |
| Do you feel you received adequate information about COVID-19 when discharged from the hospital? | n = 1788 | n = 21 | n = 212 | n = 1405 | n = 146 |
| Yes, to a high degree | 354 (20%) | 5 (24%) | 40 (19%) | 272 (19%) | 36 (25%) |
| Yes, to some degree | 440 (25%) | 3 (14%) | 62 (29%) | 333 (24%) | 42 (29%) |
| No, not at all | 447 (25%) | 9 (43%) | 53 (25%) | 367 (26%) | 16 (11%) |
| Don't know | 67 (4%) | 0 (0%) | 7 (3%) | 55 (4%) | 5 (3%) |
| I didn't receive any information | 271 (15%) | 1 (5%) | 24 (11%) | 228 (16%) | 17 (12%) |
| No discharge yet | 209 (12%) | 3 (14%) | 26 (12%) | 150 (11%) | 30 (21%) |

Note: percentages may not total 100% due to rounding

3.7 Mental health and support

The COVID-19 situation was worrisome for parents especially for those who already found themselves in stressful situations. ¹⁰ In total, 78% of all responding parents indicated that they had worried either "to a high degree" or "to some degree" about the pandemic situation during pregnancy. After birth of the infant, even 92% worried about the COVID-19 situation (*Table G6*).

Adding to this, 45% of the respondents were not offered any mental health support (including support by self-help groups, counselling etc.).

During the 40 days when my girl was in the neonatal unit, we only received information over the phone. Entry was absolutely forbidden, we held our girl again at discharge. (...) The very birth of a child is traumatic enough, and not being able to even see and touch your child for over a month is

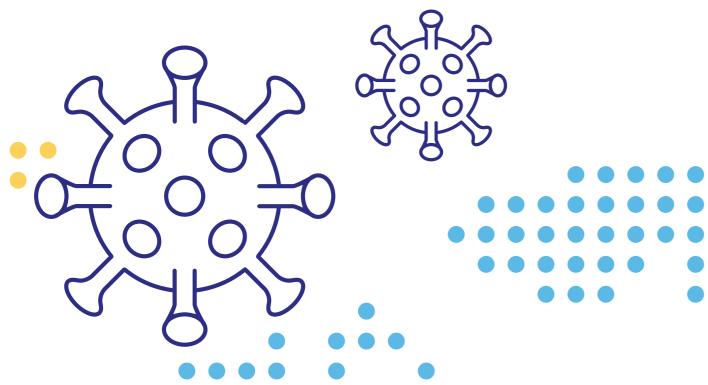
extremely hard.

(Bulgaria)

Table G6. Mental health and support

| Mental health and support | Total | Africa | Americas | Europe | Western Pacific |
|---|-------------|-----------|------------|-------------|--------------------|
| Did you worry because of the COVID-19 situation during pregnancy? | n = 1766 | n = 21 | n = 207 | n = 1391 | n = 143 |
| Yes, to a high degree | 781 (44%) | 12 (57%) | 122 (59%) | 597 (43%) | 50 (35%) |
| Yes, to some degree | 593 (34%) | 6 (29%) | 49 (24%) | 483 (35%) | 52 (36%) |
| No, not at all | 194 (11%) | 2 (10%) | 14 (7%) | 150 (11%) | 28 (20%) |
| Don't know | 17 (1%) | 0 (0%) | 0 (0%) | 17 (1%) | 0 (0%) |
| COVID-19 was not an issue then | 181 (10%) | 1 (5%) | 22 (11%) | 144 (10%) | 13 (9%) |
| Did/do you worry because of the COVID-19 situation after the birth of your baby? | n = 1765 | n = 21 | n = 207 | n = 1390 | n = 143 |
| Yes, to a high degree | 1032 (59%) | 12 (57%) | 168 (81%) | 790 (57%) | 62 (43%) |
| Yes, to some degree | 577 (33%) | 8 (38%) | 36 (17%) | 480 (35%) | 49 (34%) |
| No, not at all | 138 (8%) | 1 (5%) | 2 (1%) | 104 (7%) | 31 (22%) |
| Don't know | 18 (1%) | 0 (0%) | 1 (0%) | 16 (1%) | 1 (1%) |
| Do you feel you were adequately informed about mental health support (e.g. counselling, self-help/parent groups)? | n = 1769 | n = 21 | n = 207 | n = 1393 | n = 144 |
| Yes, to a high degree | 298 (17%) | 4 (19%) | 14 (7%) | 247 (18%) | 32 (22%) |
| Yes, to some degree | 493 (28%) | 4 (19%) | 56 (27%) | 363 (26%) | 68 (47%) |
| No, not at all | 690 (39%) | 12 (57%) | 95 (46%) | 557 (40%) | 25 (17%) |
| Don't know | 46 (3%) | 0 (0%) | 3 (1%) | 38 (3%) | 5 (3%) |
| There was no mental health support | 242 (14%) | 1 (5%) | 39 (19%) | 188 (13%) | 14 (10%) |
| What kind of support was offered? (multiple answers possible) | n = 1765 | n = 21 | n = 206 | n = 1390 | n = 144 |
| Sum of multiple answers | 2318 (131%) | 25 (119%) | 261 (127%) | 1801 (130%) | 227 (158%) |
| Psychological counselling | 578 (33%) | 4 (19%) | 46 (22%) | 492 (35%) | 35 (24%) |
| Self-help groups | 61 (4%) | 1 (5%) | 7 (3%) | 47 (3%) | 6 (4%) |
| Parent groups | 233 (13%) | 2 (10%) | 28 (14%) | 154 (11%) | 49 (34%) |
| Peer-to-peer support | 169 (10%) | 1 (5%) | 15 (7%) | 122 (9%) | 30 (21%) |
| Social worker | 375 (21%) | 1 (5%) | 46 (22%) | 260 (19%) | 67 (47%) |
| None | 792 (45%) | 15 (71%) | 109 (53%) | 638 (46%) | 29 (20%) |
| Don't know | 64 (4%) | 1 (5%) | 5 (2%) | 49 (4%) | 9 (6%) |
| Other | 46 (3%) | 0 (0%) | 5 (2%) | 39 (3%) | 2 (1%) |

Note: percentages may not total 100% due to rounding







The provision of infant and family-centred developmental care (IFCDC) has been fragmented across countries, and the COVID-19 pandemic and related restrictions have disrupted care provision even more. Specific measures to stem virus transmission were implemented across countries. Some restrictions severely impacted the application of a holistic IFCDC approach, disrespecting its evidence-based benefits, ^{25–27} which ultimately resulted in a separation of parents and hospitalised infants.

With this research, we have shed light on the magnitude of restrictive policies across countries regarding neonatal care for a most vulnerable group of patients, namely preterm, sick and low birthweight infants and their families. With the use of a multi-country online survey, we explored parents' experience with regard to IFCDC in times of the COVID-19 pandemic. Overall, 2103 parents from 56 countries shared their personal and often alarming insights. Based on the findings, it became evident that parents had to cope with severe restrictions regarding prenatal care provision, and the presence of family members, as well as with a lack of health information and much needed mental health support. These limitations in care provision, however, have immediate consequences for the infants in need and will most likely also have an impact on the long-term health status and thus the general wellbeing of the whole family.⁹

The restriction to have support persons present during prenatal appointments and birth is particularly concerning. More than one-third of all survey respondents indicated that they were not allowed to be accompanied by another person (e.g. their partner) during pregnancy-related appointments. Even half of the respondents were not allowed to have a support person present during birth. However, having a companion present is not only important for practical and informational reasons, yet most importantly also gives the expecting and birthing mother emotional support and enables non-pharmacological pain relief.²⁸ Thus, the presence of a partner or other support person substantially contributes to the wellbeing of the mother and facilitates family bonding,²⁹ which must urgently be recognised by policy-makers and local authorities ensuring a general reconsideration of current pandemic-related measures.

It is particularly worrisome that one in five of all respondents (more than 20%) indicated that no family member, including the parents, was allowed to be present with the hospitalised infant. This separation of parents and their newborns could be identified to different extents across countries. It further implies that the newborn, on the one hand, was withheld of the benefits of skin-to-skin contact and KMC, and could thus not experience hearing the parents' voices or smelling their scent. The parents, on the other hand, had less opportunities to be actively involved in the care process with immediate consequences for infant-family bonding, especially with regards to the fathers and siblings. Previous research confirms that separating parents and their newborn, however, has severe short and long-term consequences and can even impact developmental outcomes of the infant. 14,18-20,30,31 In particular KMC has substantial benefits for the health outcome of the child, which far outweighs the COVID-19 related mortality risk, as a recent two-scenarios analysis confirmed.³² Separation policies can therefore not be accepted, neither in times of the current crisis nor in future emergency situations. Thus, and in particular based on these findings, policy-makers, healthcare professionals and families together should advocate for a zero separation and inclusive policy instead.



Experiencing already difficult times by having a newborn requiring special/intensive care has been further challenged by additional stressors during the COVID-19 pandemic. Receiving adequate health information and mental health support is therefore crucial. This research showed that the majority of the participating parents worried particularly due to the COVID-19 situation – during the prenatal and postnatal period. Pre- and perinatal stress, however, poses a risk for developing postpartum depression,³³ which in turn impacts parent-child bonding with potential long-term implications for the infants' development.³⁴ Yet, communication was often lacking and health information was often not sufficiently provided. What was especially missing was adequate information about how to protect oneself and the newborn from virus transmission, during hospitalisation and also at discharge. It needs to be acknowledged that also healthcare professionals often lacked information due to the novelty of the virus which provoked additional stress and concerns as reported in a global survey among more than 1100 neonatal care professionals worldwide.²⁰ Nevertheless, thorough communication and comprehensive advice on general practices on how to protect oneself and the hospitalised infant are crucial, and will also positively influence the parents' mental health status. Especially in already challenging situations and even more so in exceptional emergency situations, mental health support at an already early stage of hospitalisation is essential.³⁵ Providing psychological support itself, including self-help groups and counselling, however, was also found to be inadequate or even not existing.

This conducted research has several strengths and limitations which merit attention. An extensive outreach and collection of data in overall 56 countries could be achieved, and detailed results of countries with more than 20 respondents per country are outlined in this report. It was possible to identify different experiences and policy approaches across countries from different continents and a variety of settings. As the questionnaire was reviewed by an interdisciplinary group of experts and pre-tested among parents, we ensured a parent-friendly wording and minimised the risk for methodological inaccuracies. The specific focus on parents and their experiences is unique and provides invaluable insights for IFCDC provision from those who are directly affected by the COVID-19 pandemic. However, due to the online format of the survey, some parents may have found it challenging to respond or could not be reached. Due to missing information regarding the newborn situation in the respective countries, we were unable to assess the representativeness of the study sample and information of nonresponders is not available. Differences regarding the point of time of data collection (with different waves of the COVID-19 pandemic throughout the year) and the hospitalisation situation might have impacted the parents' perceived experiences. Due to missing data, comparisons with pre-pandemic periods were not possible, and we acknowledge that the differences with regards to IFCDC might have already existed across and within countries before the pandemic. Finally, we were unable to receive data from some regions outside of Europe due to a missing network with local parent representative organisations or the inexistence of such organisations (also because in some countries the establishment of parent/ patient networks is prohibited).



Call to action

It is undisputed that the COVID-19 pandemic has created exceptional challenges for populations worldwide and has disrupted healthcare systems. Measures were implemented to reduce infection rates. However, some implemented restrictions have challenged neonatal care provision affecting most vulnerable groups including newborn infants and their families. Many elements of IFCDC have been severely affected, such as parental presence and skin-to-skin contact. The role of parents regarding the care of their newborn is, however, of paramount importance; separation is harmful and cannot be justified considering available scientific evidence.

IFCDC is an essential pillar of a holistic, long-term healthcare approach that benefits the overall health outcome of hospitalised infants, the mental wellbeing of their parents and families, and ultimately also the healthcare system and staff. The results of this research must therefore be acknowledged by policy-makers, public health experts, and healthcare professionals alike, to re-install a zero separation and family-inclusive policy, and an IFCDC approach where it was discontinued, to promote it where it was questioned, and to protect it where it was banned. Zero separation. Together for better care!



ACTION

FOR ZERO SEPARATION AND INFANT AND FAMILY-CENTERED DEVELOPMENTAL CARE (IFCDC)

Based on the findings of this research initiated by the European Foundation for the Care of Newborn Infants (EFCNI), and under the umbrella of the Global Alliance for Newborn Care (GLANCE), we request policy-makers, for public health experts and healthcare professionals to:



Provide every woman with a safe environment and respectful and supportive care during pregnancy, labour and birth, and allowing support persons to be present during prenatal appointments and birth.



Provide every baby born too soon, too small, or too sick with high-quality care in all settings for the best start in life.



Value, include, and empower parents as key caregivers of their newborns at all times.



Establish a zero separation and family-inclusive policy in hospitals, ensuring parental presence to enable immediate skin-to-skin and Kangaroo Mother Care, and family-infant bonding.



Prioritise mother's own milk and encourage breastfeeding when possible, emphasising the benefits of adequate infant nutrition for all newborns.



Ensure adequate provision of health information and continuous and respectful communication between healthcare professionals and parents.



Offer and provide access to mental health support to parents and families in need.



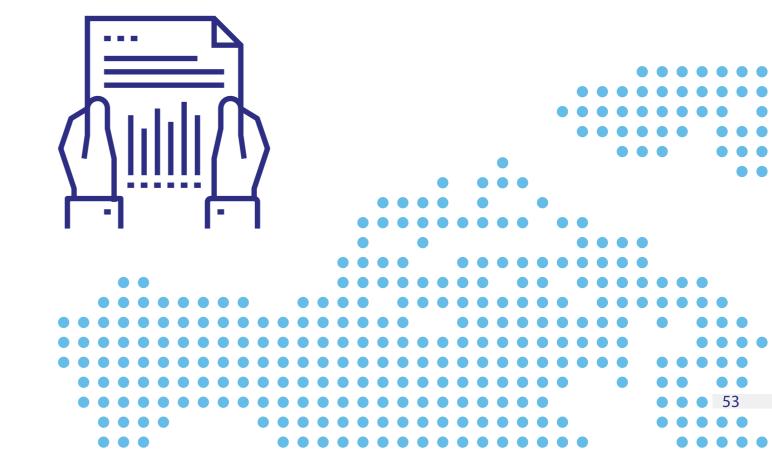
Ensure a smooth and holistic application of IFCDC in general and in times of crisis.

ZERO SEPARATION. TOGETHER FOR BETTER CARE!

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Annex

Supplementary Table S1: Country overview total participants

| | Total | n = 2094 (100%)* |
|-----------------------|---|---|
| Africa | South Africa Uganda | 23 (1%) 2 (0%) |
| Eastern Mediterranean | Afghanistan | 1 (0%) |
| Europe | Austria Azerbaijan Belgium Bulgaria Croatia Cyprus Czech Republic Denmark Estonia Finland France Germany Greece Hungary Ireland Israel Italy Moldova Netherlands Republic of North Macedonia Norway Poland Portugal Romania Russia Serbia Slovakia Spain Sweden Switzerland Turkey Ukraine United Kingdom | 12 (1%) 1 (0%) 37 (2%) 23 (1%) 1 (0%) 37 (2%) 42 (2%) 42 (2%) 1 (0%) 6 (0%) 44 (2%) 125 (6%) 36 (2%) 31 (2%) 37 (2%) 1 (0%) 38 (2%) 1 (0%) 133 (6%) 17 (1%) 49 (2%) 160 (8%) 52 (3%) 48 (2%) 1 (0%) 60 (3%) 38 (2%) 78 (4%) 2 (0%) 357 (17%) 109 (5%) 47 (2%) |
| Americas | Argentina Bolivia Brazil Canada Chile Colombia Costa Rica Ecuador Guatemala Mexico Nicaragua Paraguay Peru United States Uruguay | 9 (0%) 1 (0%) 38 (2%) 52 (3%) 7 (0%) 20 (1%) 29 (1%) 11 (1%) 41 (2%) 9 (0%) 1 (0%) 6 (0%) 11 (1%) 1 (1%) |
| Western Pacific | Australia China Japan New Zealand Singapore | 58 (3%) 61 (3%) 11 (1%) 31 (2%) 1 (0%) |

^{*}n=9 participants did not answer this question

Note: country categorisation according to the World Health Organisation regions

The Campaign "Zero separation. Together for better care!"

In light of the pandemic-related developments, the global campaign, "Zero Separation. Together for Better Care! Keep Preterm and Sick Babies Close to their Parents.", was launched under the umbrella of GLANCE. Its goal is to raise awareness for the importance of keeping parents and their babies close, highlighting the benefits of a zero separation policy for newborns in the NICU.

The campaign raises awareness for the application of a holistic IFCDC approach, even in times of crisis. Six different focus topics cover the general implications of separation policies, their impact on breastfeeding and the provision of human milk, lung diseases, the long-term effects on former preterm infants, mental health consequences, and discharge management.



For more information on the campaign "Zero Separation. Together for Better Care!" visit: www.glance-network.org/covid-19/campaign



Please also see the comprehensive set of COVID-19 related frequently asked questions (FAQ) for parents, which was developed by EFCNI in collaboration with international medical experts:

www.glance-network.org/covid-19/covid-19-faq



Supporting organisations

We warmly thank the following societies and organisations for supporting this report (in alphabetical order):



































MPT





Global

Sepsis

Alliance

Swiss Society of Neonatology















The Fetal Medicine Foundation











We warmly thank the following parent organisations for supporting this report (in alphabetical order):













































































G.B.N. - B.V.N.

Groupement Belge de Néonatologie

Belgische Vereniging voor Neonatolog









SUOMEN LASTENLÄÄKÄRIYHDISTYS RY BARNLÄKARFÖRENINGEN I FINLAND























LIETUVOS AKUŠERIŲ



















































































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Donation to GLANCE

Your donation matters!

EFCNI welcomes support of the GLANCE initiative. We would like to thank all donors for their generosity and commitment to improving maternal and newborn health on a global level. All contributions, however small, help us achieve our goals and will make a vital difference.

How to donate?



You can donate online by following this link: **Donate now**

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Imprint

European Foundation for the Care of Newborn Infants (EFCNI)

Hofmannstrasse 7a D-81379 Munich T: +49 (0) 89 89 0 83 26 - 20 F: +49 (0) 89 89 0 83 26 - 10 www.efcni.org info@efcni.org

EFCNI is represented by Silke Mader, Chairwoman of the Executive Board and Nicole Thiele, Member of the Executive Board.

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About EFCNI

The European Foundation for the Care of Newborn Infants (EFCNI) is the first pan-European organisation and network to represent the interests of preterm and newborn infants and their families. It brings together parents, healthcare experts from different disciplines, and scientists with the common goal of improving longterm health of preterm and newborn children. EFCNI's vision is to ensure the best start in life for every baby.

About GLANCE

GLANCE is a global network to represent the interests of babies born too soon, too small or too sick and their families. Initiated and coordinated under the umbrella of EFCNI, GLANCE aims at including parents from all parts of the world to exchange knowledge and experience. GLANCE aspires to decrease the burden of afflicted families and their babies born too soon, too small or too sick to help them thrive beyond survival.

For more information: www.efcni.org and www.glance-network.org © EFCNI 2021. All rights reserved.





