

Summary

Workshop “Mission: possible. Take responsibility for newborn health in Europe” 28 November 2018 – European Parliament

On 28 November 2018, the workshop on “Mission: possible. Take responsibility for newborn health in Europe” was held in the European Parliament. The workshop was organised and hosted by MEP Prof. Dr Angelika Niebler and MEP Dr Peter Liese in cooperation with the European Foundation for the Care of Newborn Infants (EFCNI). In the workshop, the European Standards of Care for Newborn Health and a Call to Action for Newborn Health in Europe were officially launched. Different speakers provided their view on possible ways of implementing the standards and of taking responsibility for newborn health in Europe.

MEP Dr Peter Liese opened the workshop by warmly welcoming the audience and introducing the speakers of this Workshop. He expressed his hope that all parties and countries benefit from a rich debate and discussion, helping to highlight the current limits and fostering the important exchange of good practice between Member States. He stressed that, on the part of politicians, the launch of the standards and the Call to Action now need to be followed by action and that children should be valued more and be a healthcare priority, considering the lives of the next generation: “A girl born today has the chance to get 100 years old – if you invest in a good start in life you avoid problems that could last for 100 years.” Dr Peter Liese pointed out that, motivated by his own professional experiences as a trained paediatrician, he has been stressing the importance of research and making it a priority. He was therefore pleased to announce that the European Commission proposed to support newborn health research with extra funding within the Horizon Europe programme.

During the workshop, the panellists conveyed their different perspectives, enriching the discussion on European Standards of Care for Newborn Health in Europe and addressed the different strategies with which countries in Europe address the challenges.

Newborn care in Europe

Dr Martin Weber, World Health Organization, Copenhagen

In his presentation, Dr Martin Weber gave an insight into neonatal mortality rates for the European region and that disparities remain evident. So far, newborn survival is not improving any more in Europe. The data he presented also showed that breastfeeding rates for exclusive breastfeeding right after birth for at least six months, are surprisingly low in Europe and that serious efforts need to be undertaken to change this situation.

Dr Martin Weber elaborated on the European strategy for child and adolescent health and stressed that we need standards also to be able to assess the quality of care, e.g. regarding breastfeeding rates, but also for the identification and management of at risk newborns. He concluded that countries need to systematically identify and address shortcomings in service delivery for newborns.

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Better statistics for better health for mothers and their babies

Dr Jennifer Zeitlin, French National Institute of Health and Medical Research, Paris

The talk by Dr Jennifer Zeitlin showed that although there is a similar access to medical knowledge, there are enormous variations in the care and support for pregnant women and newborn babies. In order to be able to learn from European success stories through working collaboratively, healthcare needs to be comparable between countries. Regarding preterm birth there are data compiled for each country but not in an international database. Certain data are not available for all countries. She pointed out that the investigation of high performing countries to promote best practices is needed.

Dr Zeitlin presented a best practice example: the EURO-PERSTAT project, which has the aim to monitor perinatal health in the EU based on valid and reliable indicators for maternal, fetal and infant health associated with pregnancy, delivery and the postpartum period. There are several (10) core indicators, and 20 additional (recommended) indicators. The latest Euro-Peristat Report, has been published in November 2018, showing data from 2015 and enormous differences between European countries regarding neonatal mortality at 22 weeks of gestation (range: 1.5-3.0 per 1000, and an overall decline of 10% compared to 2010, but high heterogeneity), percentage of preterm birth (range: 5.4-12.0%, and stable rates compared to 2010) and high disparities in the caesarean section rates.

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The place of birth makes the difference – a patient's view

Livia Nagy Bonnard, Melletted a helyem Egyesület, Budapest

Livia Nagy Bonnard presented a patient's personal view on how the place of birth can significantly influence the health and life of a preterm baby and his/her family. Having suffered from a severe pre-eclampsia and the following consequences of preterm birth, Livia shared her experiences of how challenging the situation of parents of a preterm child can be and how different healthcare systems and approaches between countries and subsequent differences in care led to life-long challenges for her child and her family.

As co-founder of the Hungarian parent organisation Melletted a helyem Egyesület, she has been committing herself for families with a similar destiny and built up a support network in Hungary, fostering the exchange and communication between healthcare professionals and parents and pushing forward the implementation of family-centred care approaches in Hungary. As a contributing parent representative to the newly launched European Standards of Care for Newborn Health, she is confident that a mind-change can be achieved in many more hospitals units than up to now and that the burden for families can be reduced by working together.

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The importance of effective follow-up of preterm babies: reducing burden, enhancing quality of life

Prof. Dr Dr Dieter Wolke, The University of Warwick, Coventry

Prof. Dr Dr Dieter Wolke elaborated on the importance of effective follow-up of preterm babies to enhance their quality of life. Life course tasks include family/sibling relationships, friendships, romantic and sexual relationships, independence and happiness/life satisfaction. Whereas most of these life course tasks start at a certain age, happiness and life satisfaction are life course task that play a role during the whole life of an individual.

Research showed that preterm born babies have lower chances to achieve life course goals, such as higher education, employment, romantic or sexual relationships, or parenthood. The aim of follow-up and continuing care is to help preterm babies improve their quality of life by arranging appropriate support and care pathways. Assessments of child and family functioning in early childhood and during transition to school are very important, but also to set realistic expectations. Follow-up is essential to support former preterms in living a normal, independent life. Dr Wolke pointed out that choosing the right time slots for follow up is crucial (e.g. at transition to school); as well as a proper case management to secure quality and to involve parents in follow-up.

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How can Europe meet challenges in newborn health standards?

Prof. Dr Mats Eriksson, Örebro University, Örebro

Prof. Dr Mats Eriksson explained that neonatal care constantly develops and especially parental involvement increased in the last years. To achieve high quality neonatal care and the best outcome for the baby and the family, teamwork is essential. Parents should be seen as the primary caregivers and be encouraged to provide the care for their baby. Furthermore, he pointed out, there is a need for safe, sustainable, and productive staffing. Studies have shown that a higher proportion of nurses with a university degree decreases mortality. Thus, the proportion of specialised nurses and the education have to be improved and parents should be involved in the care to meet the challenges of preterm birth. He called upon politicians that the more you invest into perinatal and neonatal care, the less you have to act in later life. Welcoming the launch of the standards, Prof. Dr Eriksson concluded that neonatal care should be organised around the principles of family-centred care, individualised developmental supportive care and a minimum set of standards in all important areas

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Optimal feeding of our babies – an investment into future population health

Prof. Dr Berthold Koletzko, Ludwig-Maximilians-University, Munich

Preterm babies are born at a time when they are not yet ready for normal feeding. Prof. Dr Berthold Koletzko reminded the audience that extremely preterm babies are considered nutritional emergencies, as they have high nutrient needs per kilogram but immature feeding ability and digestive tract functions. Besides this, their brain is especially sensitive during this development stage. Poor nutrition will effect brain growth negatively with long-term consequences for the child and supporting breastfeeding is key.

In addition, initial administration of parenteral nutrition, early enteral nutrition (ideally with fortified human milk) and post-discharge nutrition play an important role for the development of preterm babies. Therefore, professional nutritional care of preterm infants is key for healthy growth, long-term health and development, and quality of life. As nutritional care practices in Europe significantly, each hospital should develop standard protocols on nutrition care, train staff accordingly, and audit the implementation of these protocols. Prof. Koletzko encouraged his colleagues: "It's not enough to read the standards, talk about them and implement them".

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Value based newborn healthcare – measuring the results of treatment that patients experience

Prof. Dr Andreas Flemmer, Dr. v. Haunersches Kinderspital am Perinatalzentrum
Grosshadern, Munich

Prof. Dr Andreas Flemmer introduced his talk with the thought that preterm infants are a very valuable group of patients, as any investment in their health results in lifelong sustainability for them, their families, and the society. Currently, there is a wide variation in health outcomes across Europe and beyond. Against this background, the International Consortium for Health Outcomes Measurement (ICHOM) is developing an outcome measurement which drives value improvements for all stakeholders.

The aim of the newly founded collaboration between EFCNI and ICHOM under the scientific leadership of Prof. Flemmer is to balance a comprehensive view of measurement for evaluating preterm and hospitalised newborn infants with a feasible recommendation that providers can reliably implement. For this purpose, a minimum Standard Set will be developed which will enable outcome measurement in routine clinical practice to improve decision making between providers and patients, to facilitate quality improvement, and to allow for benchmarking across organisations.

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The power of patient organisations – the impact on national health systems during an economic crisis

Dr Eleni Vavouraki, Ilitominon, Athens

The talk by Dr Eleni Vavouraki showed that patient organisations do have an impact even when funds are scarce, for example during an economic crisis. In 2011, when she founded her parent organisation Ilitominon in Athens, only one milk bank existed in Greece and the average nurse-patient ratio was (and still is) 1:6 and the staff felt exhausted and discouraged.

The work of Ilitominon proved that activating volunteers worked out well. Next to various support activities for parents of preterm babies and awareness campaigns, the organisation managed to introduce the Family and Infant Neurodevelopmental Education Programme (FINE) in Greece. Thanks to the FINE training, the staff satisfaction improved because the team work between parents and staff relaxed the tense working situation. Dr Vavouraki stressed that success requires commitment, conviction and a vision and the believe to find a solution.

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European standards of newborn care: paving the way for a healthier population

Prof. Dr Charles Roehr, President of the European Society for Paediatric Research (ESPR)

Prof. Dr Charles Roehr pointed out that preterm birth is a risk factor for death and life long illness. Inequality of healthcare and care provision in Europe results in differing outcomes and life-long consequences for babies. He stressed that to address these issues, it is important that doctors and nurses are being trained according to agreed professional standards. The European Society for Paediatric Research (ESPR) and the European Foundation for the Care Newborn Infants (EFCNI) therefore collaborate to work towards the common goal of harmonising neonatal training and care throughout Europe.

In 1999, the UEMS Paediatric Section and *European Board of Neonatology* (EBN = ESPR's educational arm) published the 1st EU Curriculum and Syllabus for Training in Neonatology. In 2018, the 3rd edition has been published and standards on Education and training have been developed within the ESCNH project. For the benefit of babies and their families, ongoing support is needed to promote uniform implementation of these standards and cutting-edge research in Europe.

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Newborn health standards – improving quality of care across Europe

Silke Mader, European Foundation for the Care of Newborn Infants, Munich

As Silke Mader explained in her talk, around 700,000 babies are born preterm in Europe every year, ranging from 6.3-13.3 % of all live births in Europe. These babies receive extremely different care as there are enormous differences in the infrastructure for high-risk pregnancies, in the organisation of medical centres, transport systems, education of healthcare professionals, follow-up and continuing care, medical treatment, level of implementation of infant- and family-centred care, nutrition and NICU design. These differences have an impact on outcome and long-term consequences of preterm babies.

Therefore, she emphasised, it is very important to work together with all relevant stakeholders in this unique project, initiated by patient representatives for patients, and in which parents are involved in every step of the development process. The newly developed European Standards of Care for Newborn Health are now supported by 158 professional healthcare societies and parent organisations and cover the complexity of neonatal care, promoting an equitable care and high levels all around Europe (and beyond).

Silke Mader concluded: "This mission is possible! Therefore, we Call to Action for Newborn Health in Europe, to support the implementation of the standards all over Europe!"

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Discussion and Closing

In the following discussion, MEP Prof. Dr Angelika Niebler reaffirmed her commitment for the implementation of the standards and the Call to Action. She stated that “in the next workshop in the European Parliament in the coming years, we will be able to prove first successes in the implementation of the standards”.

Following the comments from the audience, it was supported that the different stakeholders have been following the right track towards an improvement and harmonisation of neonatal care within Europe, but that much more action has to be undertaken to increase understanding between healthcare professionals and parents, foster education and training, and work towards obsolete healthcare practices.

At the end of the workshop, all the participants, speakers and audience from different disciplines, solemnly signed the Call to Action and committed themselves to an imminent implementation of the standards in their countries.

View more:

- [Download to the European Standards of Care for Newborn Health](#)
- [Download the Call to Action](#)