

# Shaping the future

Combining forces to improve newborn health



## European Standards of Care for Newborn Health **Toolkit**



european standards of  
care for newborn health

**EFCUNI** european foundation for  
the care of newborn infants

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# Personal greeting

Dear colleague, dear friend, dear supporter,

First of all, we would like to thank you for supporting the European Standards of Care for Newborn Health as well as the great collaboration and your trust!

One year has passed since the official launch of the European Standards of Care for Newborn Health in the European Parliament in Brussels. We were and still are overwhelmed by the attention the standards received and the commitment for their promotion and implementation. Meanwhile, over 170 professional healthcare societies and parent organisations officially support the standards, and there is almost no congress around Europe where they are not a subject on the agenda!

We proudly present you this toolkit and warmly invite you to join the promotion of the standards and to work with us on their implementation on a national, regional, and local level. Help us to ensure that all preterm and ill babies receive the highest quality healthcare from the very beginning and thus, the best chances for their lives no matter where they are born. With combined forces, we will improve the care for babies in the long term.

Changes in healthcare policies start at a national and even quite often on a regional or local level and every one of you can make a difference. This toolkit will give you guidance on how to identify actions required in your country and to put national standards of care for newborn health into practice – while always taking the European Standards of Care for Newborn Health as a point of reference.

To assist you in this process, this toolkit provides you with knowledge and background information about the standards, ideas, tools, and step-by-step advice. Many practical examples serve as an inspiration in order to raise awareness and engage with national stakeholders. The toolkit has been developed as a handbook to address challenges, to find opportunities for improvement, to provide practical advice, and to help you make your voice heard within the professional discourse and through political advocacy.

All downloadable documents are linked in the toolkit and are also available on our project website:

**[www.newborn-health-standards.org/downloads](http://www.newborn-health-standards.org/downloads).**

Hopefully you find the toolkit helpful and that it will serve you to foster the national implementation of the European Standards of Care for Newborn Health in your country!

We are keen on hearing more from you and your activities. Furthermore, we would be very interested to learn whether the toolkit is helpful for you and what experiences you gained, which we could share via our newsletter. Should you have any news to share or have any questions, please do not hesitate to contact us via email: **[standards@efcni.org](mailto:standards@efcni.org)**.

Yours,



**Silke Mader**  
*Chairwoman of the  
EFCNI Executive Board*



**Professor Neil Marlow**  
*Member of the  
EFCNI Executive Board*



**Nicole Thiele**  
*Vice Chair of the  
EFCNI Executive Board*



**Aurelia Abenstein**  
*Director, Administration  
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**Professor Luc Zimmermann**  
*Senior Medical  
Director*



# Introduction

Welcome and thank you for being part of the network of supporters of the European Standards of Care for Newborn Health – in the following referred to as ‘the standards’. This practical toolkit will give you a broad overview on the steps you can undertake to make the implementation of the standards become reality in your country.

## The scope of this toolkit

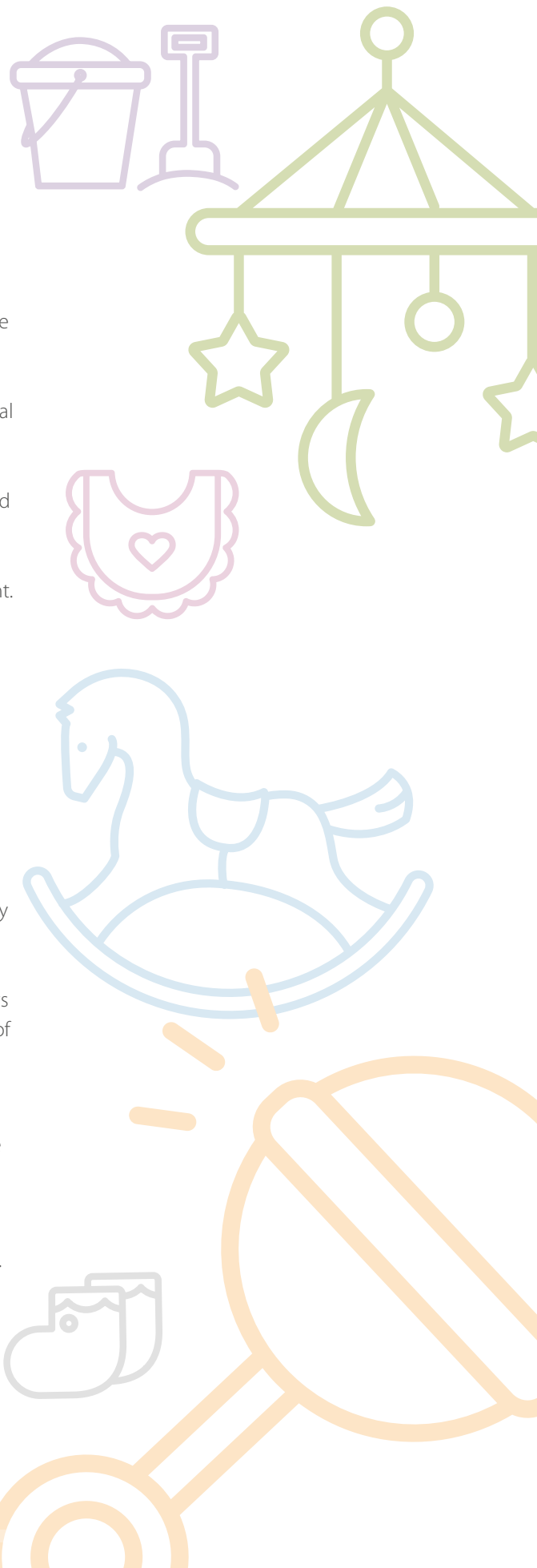
The toolkit aims to facilitate and support the implementation of the standards on a national, regional, and local level based on the European Standards of Care for Newborn Health. It can be used by many different stakeholders like parent organisations, health-care professionals, healthcare societies, payers, non-governmental organisations, policymakers, politicians, the media, and other interested parties. It is very important to keep in mind to work together with all stakeholders involved in the care of preterm and ill babies (e.g. neonatologists, paediatricians, nurses, midwives, parent representatives, hospitals, and insurances). Only if all of these stakeholders work together, advocacy work can be efficient. This aspect also reflects the general idea of the European Standards of Care for Newborn Health project – to involve a multidisciplinary team of experts and parent representatives.

## How can this toolkit help you?

Consulting this toolkit, it will provide you and other stakeholders with practical information and tools to assess and improve the health of preterm and ill babies in their respective countries. It is not intended to be prescriptive and recognises that each country is at different stages on the path towards improving newborn health. What already runs optimally in one country might be improvable in another and vice versa. Thus, the toolkit also shows how countries can learn from each other through an exchange of experience.

It will also assist you in professionalising and increasing your outreach and give advice in articulating your demand to change clinical practice and policy in your country.

Please note that the activities and ideas which are presented in this document are to stimulate internal discussion and thoughts. All appropriate local legal, regulatory, medical and ethical practices and approvals must be obtained and complied with.



# Introduction

## What does this toolkit offer?

This toolkit offers a full range of concepts, resources, support, ready-to-use tools, as well as clear milestones and objectives by which progress can be assessed. Besides, you will learn how to engage with a broad range of stakeholders. It contains the following core elements with regards to the implementation of the European Standards of Care for Newborn Health: Following a brief introduction to the European Standards of Care for Newborn Health, there is described background information and tips giving you a sound basis to get started in your country. It also suggests options and methods to establish and/or to improve a dialogue with key stakeholders to deliver upon the ultimate goal – to improve the clinical practice and the policy environment around the care of preterm and ill babies. You will learn more about how policy and advocacy activities can help you achieve substantial changes, both on a European, a national, regional, and local level. Each chapter presents diverse tools, underlined with best practice examples by EFCNI and several collaboration partners.

The chapters can be read sequentially, however given the richness of each chapter it may be wise to read only those chapters that specifically address your current needs. The toolkit will also be continuously developed further and extended with new content/chapters. Do not miss to check [\*\*www.newborn-health-standards.org/downloads\*\*](http://www.newborn-health-standards.org/downloads) for updates. Please also let us know via [\*\*standards@efcni.org\*\*](mailto:standards@efcni.org) if you are missing any content or if you have comments. We will do our best to plan new content according to your wishes.

Consulting this toolkit, you will be able to:

- Promote preterm and newborn health into a priority in need of attention, improved policies and practices, as well as resources
- Build relationships with an expanded pool of stakeholders and to work with key advocates to raise awareness on preterm birth issues
- Drive improved national, regional, and local preterm and neonatal prevention, treatment and care, shaping and harmonising national guidelines
- Set up professional and effective steps and measures to help you foster the implementation of national standards based on the European Standards of Care for Newborn Health



### NOTE

To download the materials and access the links outlined in this toolkit, please refer to the digital version available at: [\*\*www.newborn-health-standards.org/downloads\*\*](http://www.newborn-health-standards.org/downloads).

CHAPTER

# Background Information



# Background information

## Overview

- About the European Foundation for the Care of Newborn Infants (EFCNI)
- Preterm birth in Europe – numbers and key facts
- Data and supporting evidence base
- About the European Standards of Care for Newborn Health project
- Statements of standards per Topic Expert Group
- FAQs

In the following, you find background information about the European Foundation for the Care of Newborn Infants (EFCNI), preterm birth in Europe as well as the European Standards of Care for Newborn Health project and the individual standard topics.

Consulting this toolkit, you will know:

- More about the European Standards of Care for Newborn Health – in the following ‘the standards’
- Where to look for data on preterm birth and how to collate evidence
- Develop your own arguments for implementing the standards



NOTE

To download the materials listed in this toolkit, please go to:  
**[www.newborn-health-standards.org/downloads](http://www.newborn-health-standards.org/downloads)**.

## About the European Foundation for the Care of Newborn Infants (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 long-term health of preterm and newborn children. EFCNI's vision is to ensure the best start in life for every baby independent of the place of birth.

In order to achieve this, EFCNI has three main areas of work:



### Preconception and maternal care

We want to ensure widely accessible pregnancy information and the provision of effective, equitable high-quality care for all women of reproductive age.

### Treatment and care

We aim at continuously improving treatment and care for all preterm babies and ill newborns as well as support for their families.



### Follow-up and continuing care

We seek to improve the long-term health and quality of life of preterm babies and ill newborns. This also includes the provision of medical, psychological, socio-paedagogical, and financial support for these children and their families.

# What we do

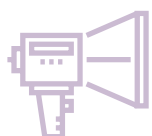
EFCNI is an advocate for preterm babies, ill newborns, and their families. Our work is dedicated to improving the situation of pregnant women and newborns in Europe across the full spectrum of care, promoting and protecting the right to the best start in life. Our work is based on the following three pillars:



### Establishing a powerful network

We combine forces of all stakeholders involved and foster collaboration to achieve our common vision by:

- Partnering with parents, healthcare professionals, scientists and their respective societies as well as with policy-makers, international non-profit and private sector organisations
- Empowering national parent organisations through networking events, special trainings and workshops



### Raising awareness

We call attention to the growing challenge of preterm birth and its significant impact on children, families, and our society by:

- Running awareness campaigns
- Constructive dialogue with political decision-makers and opinion-leaders
- Making the patient's voice heard in the healthcare setting



### Sharing best practice

We develop and disseminate knowledge to improve and implement high-quality treatment and care by:

- Coordinating interdisciplinary projects
- Providing easy-to-understand and widely accessible information for families and professionals
- Participating in research and providing advice from the patient's perspective
- Organising and hosting conferences, workshops, and roundtables
- Developing factsheets and position papers

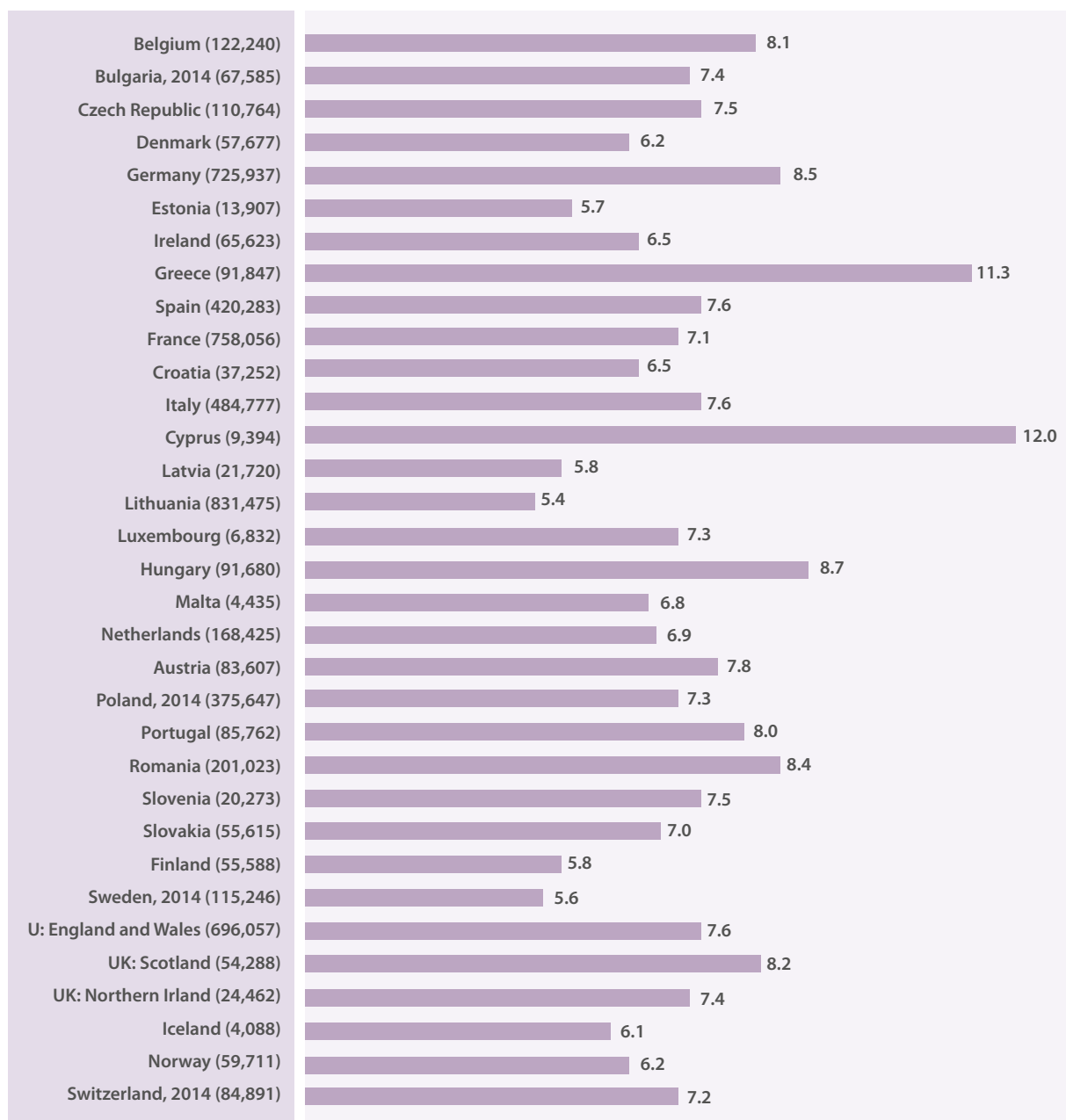
For more information  
about EFCNI, please  
visit: [www.efcni.org](http://www.efcni.org).



## Preterm birth in Europe – numbers and key facts

When a baby is born before the completion of 37 weeks of pregnancy, the baby is born preterm. In Europe, as in the rest of the world, preterm birth is one of the leading causes for neonatal mortality and accounts for more than half of all infant deaths. Although the survival rate for preterm babies is continuously improving thanks to advances made in medical science, preterm birth is a remaining challenge with different trends in Europe. Also, long-term morbidity still represents a major problem. Another remarkable aspect is the difference in frequency of preterm births throughout Europe. Overall, preterm birth rates in Europe ranged from about 5,4% in Lithuania to 12% in Cyprus in 2015.<sup>1</sup>

### Percentages of preterm live births in 2015



<sup>1</sup> Euro-Peristat Project. European Perinatal Health Report. Core indicators of the health and care of pregnant women and babies in Europe in 2015. November 2018. Available from [www.europeristat.com](http://www.europeristat.com).

## PRETERM BIRTH



40 WEEKS

A baby is born preterm, when it is born

**before 37 weeks of gestation.**

DEPENDING ON THE LENGTH OF PREGNANCY, IT IS DIFFERENTIATED:

**extremely preterm:**

less than 28 weeks of pregnancy

**very preterm:**

28 to 31 weeks of pregnancy

**moderate to late preterm: baby**

32 -37 weeks of pregnancy

**1 baby in 10**

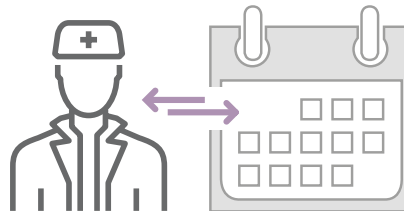


**is affected by preterm birth**

**Prematurity can affect health throughout the whole life**



**REGULAR FOLLOW-UP ASSESSMENTS ARE IMPORTANT**



**Babies born preterm face higher risks of poorer long-term neurodevelopmental outcomes**

e.g. cerebral palsy, visual and hearing impairments and mortality



**PREMATURITY**

**is the main cause of death under 5 years**

**THE EARLIER a baby is born THE HIGHER is the risk for poorer long-term outcomes**

**not every**

preterm born baby has a poor long-term outcome

## Risks and possible causes for preterm birth

Several demographic, lifestyle, and medical factors have been identified that may increase the risk of preterm birth. A healthy lifestyle, prevention, and treatment of diseases as well as regular antenatal care on the other hand, may contribute to a term birth.<sup>2,3</sup> However, in about 50% of preterm births, the actual cause of early delivery as well as possibilities of prevention remain unknown.

Lifestyle factors	Medical conditions	Demographic factors
Smoking	Infections (urinary tract, vaginal)	Aged under 17, or over 35
Alcohol consumption	High blood pressure	Low socioeconomic status
Drug use	Diabetes	Ethnicity
High stress level & long working hours	Clotting disorders	
Late/no prenatal care	Underweight	
Lack of social support	Obesity	
	Multiple pregnancy	
	Women having experienced preterm birth before	
	Uterine or cervical abnormalities	



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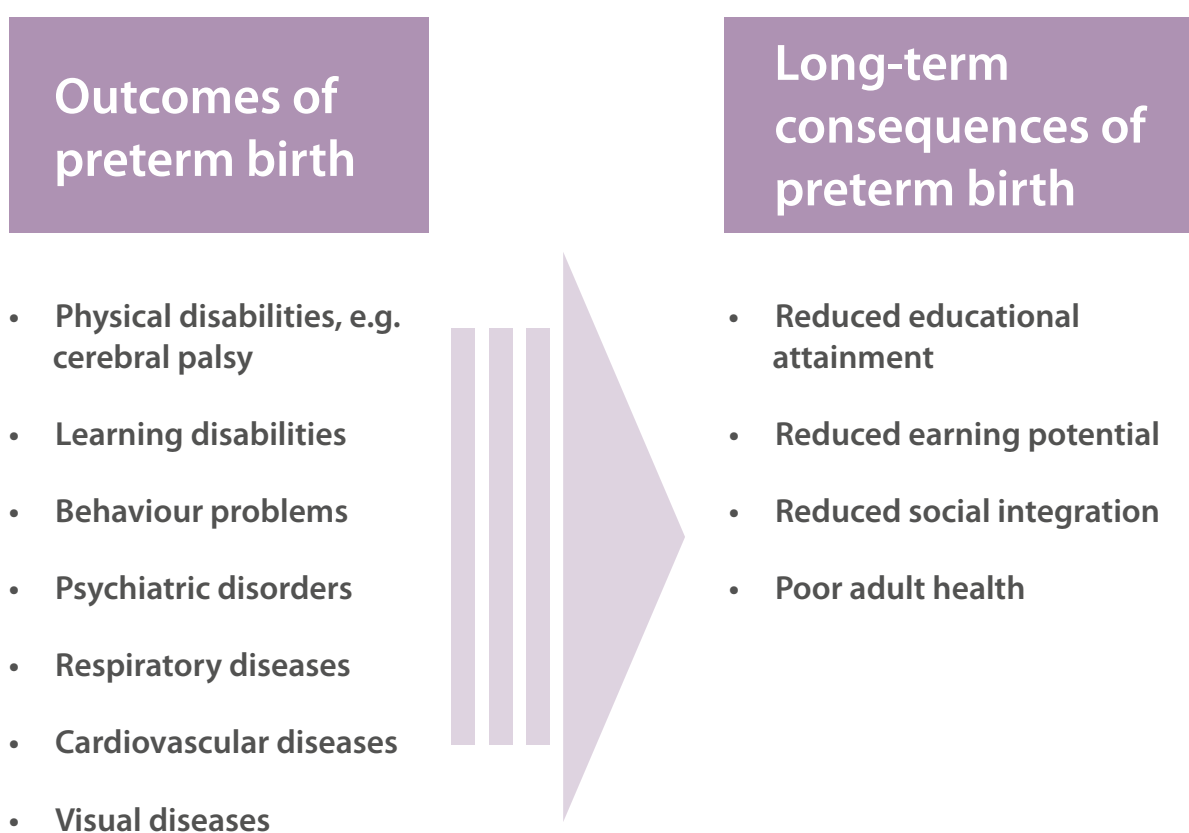
<sup>2</sup> Born Too Soon: The Global action report on preterm Birth. World Health Organization; 2012

<sup>3</sup> Zeitlin J, et. al. International Journal of Obstetrics. Gynaecology. 2013;120(11):1356–1365.

### Potential consequences of preterm birth

Preterm birth can result in various long-term impairments regarding both the physical and mental development of the child. Yet, preterm birth does not only impact the child's own health and development. It also strongly affects the parents and other family members on a psychological, social but also on a financial level. Finally, preterm birth also takes its toll on society, creating a financial burden on the healthcare system as such, since later morbidity poses significant economic costs in terms of healthcare, education, and social benefits.

### Outcomes and long-term consequences of preterm birth<sup>4</sup>



In general, one can say the lower the gestational age at birth, the less developed the organs and therefore, the higher the risk for long-term disability.<sup>5</sup> Additionally, although the use of evidence-based practices such as non-invasive respiration methods for instance, has been shown to improve survival without severe morbidities for very preterm babies, at the moment, not every preterm baby in Europe receives evidence-based treatment.<sup>6</sup>

For more information about preterm birth in Europe, please download EFCNI's factsheet on preterm birth at: [www.efcni.org/activities/downloads/factsheets](http://www.efcni.org/activities/downloads/factsheets).

<sup>4</sup>Keller M, Saugstad OD, van Steenbrugge G, Mader S, Thiele N. Caring for Tomorrow. EFCNI White Paper on Maternal and Newborn Health and Aftercare Services [Internet]. European Foundation for the Care of Newborn Infants (EFCNI); 2011.

Available from: [www.efcni.org/wp-content/uploads/2018/03/EFCNI\\_WP\\_01-26-12FIN.pdf](http://www.efcni.org/wp-content/uploads/2018/03/EFCNI_WP_01-26-12FIN.pdf)

<sup>5</sup>Platt MJ. Outcomes in preterm infants. Public Health. 2014 May;128(5):399–403.

<sup>6</sup>Chang HH, Larson J, Blencowe H, Spong CY, Howson CP, Cairns-Smith S, et al. Preventing preterm births: analysis of trends and potential reductions with interventions in 39 countries with very high human development index. The Lancet. 2013 Jan;381(9862):223–34.

## Data and supporting evidence base

### How to find medical literature

The previous mentioned information can only give you a glimpse of the information that exists on preterm birth in general and on the specific health challenges a preterm baby or an ill baby might face. Therefore, it is important to know where you can look for further valid medical information.

There are diverse search engines which you can use to search for medical information. Some of them can only be accessed with a subscription e.g. via a university account, but there are also some very informative, publicly available, free sources you might want to use:

Search engine	Website	Tutorials and support
Pubmed	<a href="http://www.ncbi.nlm.nih.gov/pubmed">www.ncbi.nlm.nih.gov/pubmed</a>	<a href="http://www.nlm.nih.gov/bsd/disted/pubmedtutorial">www.nlm.nih.gov/bsd/disted/pubmedtutorial</a> <a href="http://www.bit.ly/PubMedHelp_NCBI">www.bit.ly/PubMedHelp_NCBI</a>
Google Scholar	<a href="https://scholar.google.com">https://scholar.google.com</a>	<a href="https://scholar.google.com/intl/en/scholar/help.html">https://scholar.google.com/intl/en/scholar/help.html</a>
ScienceDirect	<a href="http://www.sciencedirect.com">www.sciencedirect.com</a>	<a href="https://service.elsevier.com/app/home/supporthub/sciencedirect">https://service.elsevier.com/app/home/supporthub/sciencedirect</a>

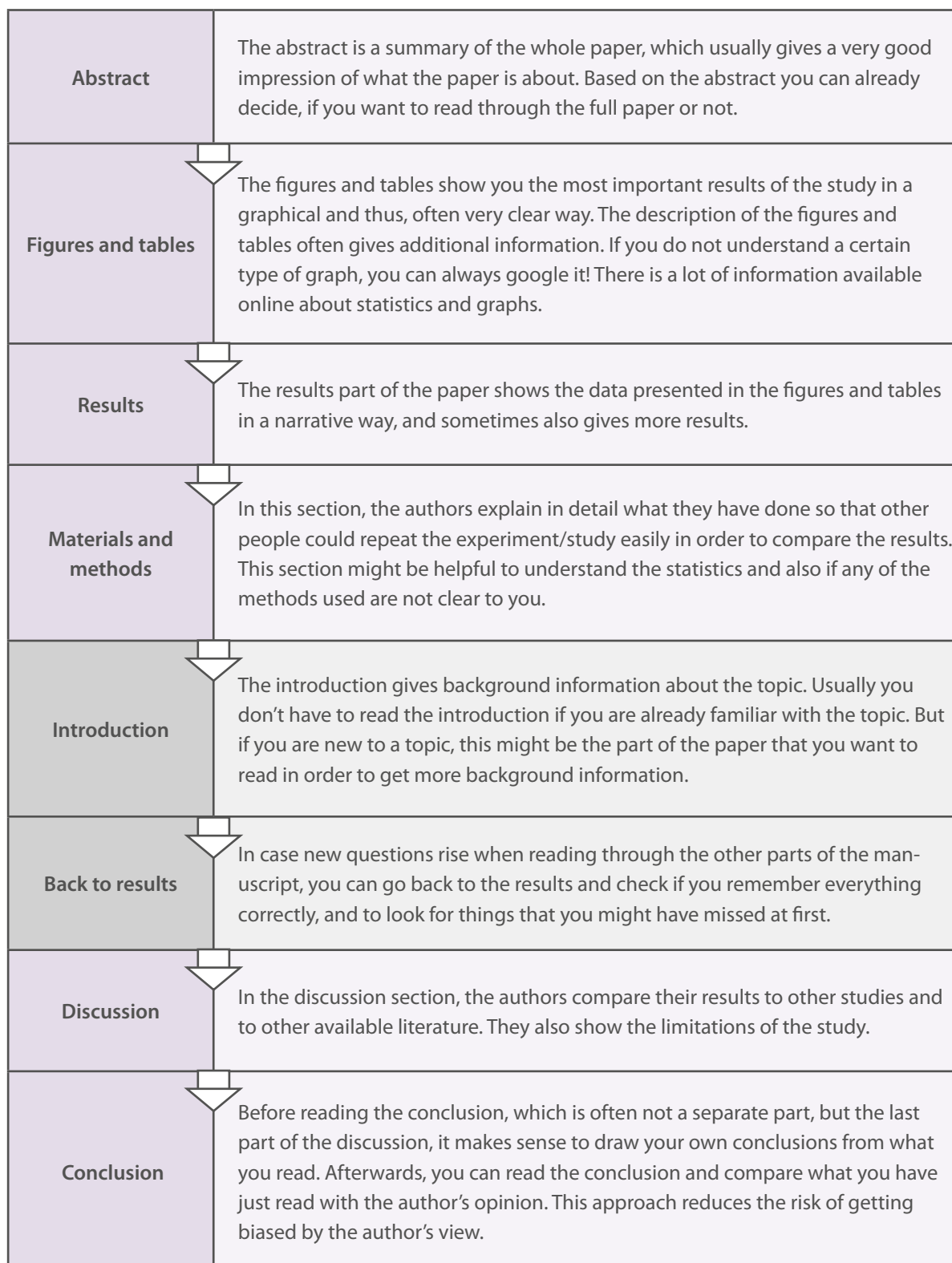
Each of these search engines works a bit different, therefore take your time to get familiar with these tools and choose the one that suits you best. For further assistance, check out the support pages and tutorials of these engines.

### How to read a scientific paper

When your search for further information has been successful, you usually end up with a list of titles and/or abstracts of manuscripts that might be of interest for you. Reading through the titles already gives you a glimpse of what the paper is about and you can decide if you want to continue with reading the abstract. Reading the abstract can help you to define if it is worth for you to read the whole article or study. Sometimes the full manuscript is available for free, but often it is required to have a subscription to the respective platform providing the paper, to get full access. Do not let this stop you from your research! In this case you can always write to the corresponding author (usually a contact email can be found together with the abstract) and ask him/her for sending you the full paper. This approach works in a lot of cases, as most authors are happy to share their work with an interested audience. If it does not work, you can always also buy a paper.

Once you have the full paper, you can continue with your research for information by reading and evaluating the information the paper provides. It is helpful to understand how a scientific paper is structured to facilitate this process. Usually, every paper has a similar structure. There is always an **abstract** at the beginning of each paper, followed by the **introduction** or sometimes also called **background** section. The next part is usually the **materials** or **methodology** part, followed by the **result** section. The last part of a paper is always the **discussion** sometimes including a **conclusion**. The conclusion can also be a separate part.

The following flow chart gives you an option of finding your way through a paper in a slightly different structure/ order than the paper is written in. But of course, you can always start at the beginning and read until the end of the paper.





## What is scientific evidence?

This chapter deals with how you can use data and scientific evidence for your argumentation to implement the standards. But when exactly can a finding or a practice be considered as scientific evidence? Basically, scientific evidence results when a theory or assumption is tested by different people independently in experiments, and can be seen as facts (e.g. the results of a study) that can either support or disapprove a scientific theory or assumption.

## Substantiation of your claims with scientific evidence helps you to:

- Be taken seriously
- Create media interest based on a credible case
- Build confidence for your cause
- Capture a stakeholder's attention
- Have a well-grounded discussion with medical experts
- Show variation in health service delivery and thus, support your cause
- Question government prioritisation of prematurity and your national health service delivery
- Drive policy and practice change in support of your overall and local objectives
- Highlight facts and statistics in support of your positioning and recommendations that can be used to add credibility and weight to discussions
- Support the implementation of standards of care for preterm and newborn health



### NOTE

In order to substantiate your point and add credibility to your proposition to implement the standards, data and evidence play a crucial role in helping you to demonstrate your key audiences why action needs to be taken to improve care for preterm and ill babies.

### Where to find statistics on preterm birth for your country?

As you aim to push the implementation of the European Standards of Care for Newborn Health forward on a national level, you need to find statistics on preterm birth referring to your own country. Having national numbers at hand will also help you in discussions with political decision makers and other stakeholders as you will be able to substantiate your argument with facts. Here is how you can find the numbers and use them for your cause.

- Look online for an office or an institution for national statistics or the equivalent body in your country which is in charge of collecting, producing, and providing independent statistical information for different topics. Amongst these you may find birth statistics and hospital data. Relevant data for you could be:

How many babies are born every year in your country? .....

How many babies are born preterm every year in your country? .....

How many babies are born extremely preterm each year? .....

How high is the survival rate of preterm babies depending on the week in which the babies are born? .....

How high is the survival rate of preterm babies depending on the week in which the babies are born in your hospital? .....

What are the long-term outcomes of preterm babies? .....

- Get in touch with your national healthcare professional societies (neonatology, gynaecology, perinatology) about these numbers, they might collect them on a regular basis
- If there is no national statistics on these topics for your country available, have a look at the Euro-Peristat<sup>7</sup> report, which provides information about maternal and newborn care in 31 European countries ([www.bit.ly/Euro-Peristat](http://www.bit.ly/Euro-Peristat)) (see this chapter: [Excursus Euro-Peristat](#))
- Another option for finding out these relevant numbers is to contact the respective ministry e.g. the ministry of health or other regional health authorities or approach parliamentarians involved in health topics in your country. They, in return, can address their government in regards of data and numbers about preterm birth
- Take an economic approach and look for data on the cost of prematurity in your country. Health insurances, university hospitals, local NGO's or political parties might provide information about this subject. Questions you can look into in detail could be:

What are the costs for a preterm baby in the NICU? .....

What does it cost when a child needs special therapies after discharge? .....

How big is the loss of earnings for a family in average, if one parent cannot go to work after a preterm birth?  
.....

<sup>7</sup> Euro-Peristat Project. European Perinatal Health Report. Core Indicators of the Health and Care of Pregnant Women and Babies in Europe in 2015!

**NOTE**

Further possible sources for information on statistics on preterm birth could be:



## There is no data? Turn the lack of evidence into a powerful campaigning tool

In several countries, data on the impact and costs of prematurity are routinely collected. Contrary, in other countries there is a lack of these data. Having no data available, in fact not compiling such data in the first place, is an unacceptable situation. Therefore, turn this situation into a campaigning tool!

A lack of evidence enables you to:

- Create media attention to this issue
- Highlight the need for improved data collection around prematurity and associated topics
- Form a coalition of parent groups and healthcare professionals to improve data collection and research – this collaboration will also support you in the implementation of the standards
- Question how the government/ministry can evaluate the quality of care their healthcare system provides for preterm and ill babies, if there are no data available
- Find a parliamentary advocate/supporter who can lobby for your cause, addressing the government/ or minister of health/education/social affairs directly by asking parliamentary questions, or writing to the relevant minister and officials



### NOTE

- After you identified national evidence base, use this data to develop targeted messages
- Use targeted messages to directly address different stakeholders
- For more information, please see chapter **Advocacy on EU and national level** and chapter **Communication: Communication strategy**

### Excursus Euro-Peristat – a reliable source for health information:

Euro-Peristat is a European research project that aims to improve perinatal health. They established a European information system to assess perinatal health problems and their causes, and to check if certain policy changes show any improvements over time.

Euro-Peristat makes **data available** in

**reports**, on their **website** and in **scientific publications**. **European Perinatal Health Reports** were so far **published in 2008, 2013 and 2018**.



Euro-Peristat is coordinated by INSERM (Institut national de la santé et de la recherche médicale), **a public scientific research institute** which operates under the joint authority of the French Ministries of Health and Research. It is funded under the European Joint Action InfAct, which **aims to develop sustainable health reporting in Europe**. Euro-Peristat's network includes **over 100 data providers in 31 countries**.

To download the latest report please visit: **[www.bit.ly/Euro-Peristat\\_overview](http://www.bit.ly/Euro-Peristat_overview)**.

Please see chapter **Materials** to find out how to use the Euro-Peristat for your communication.

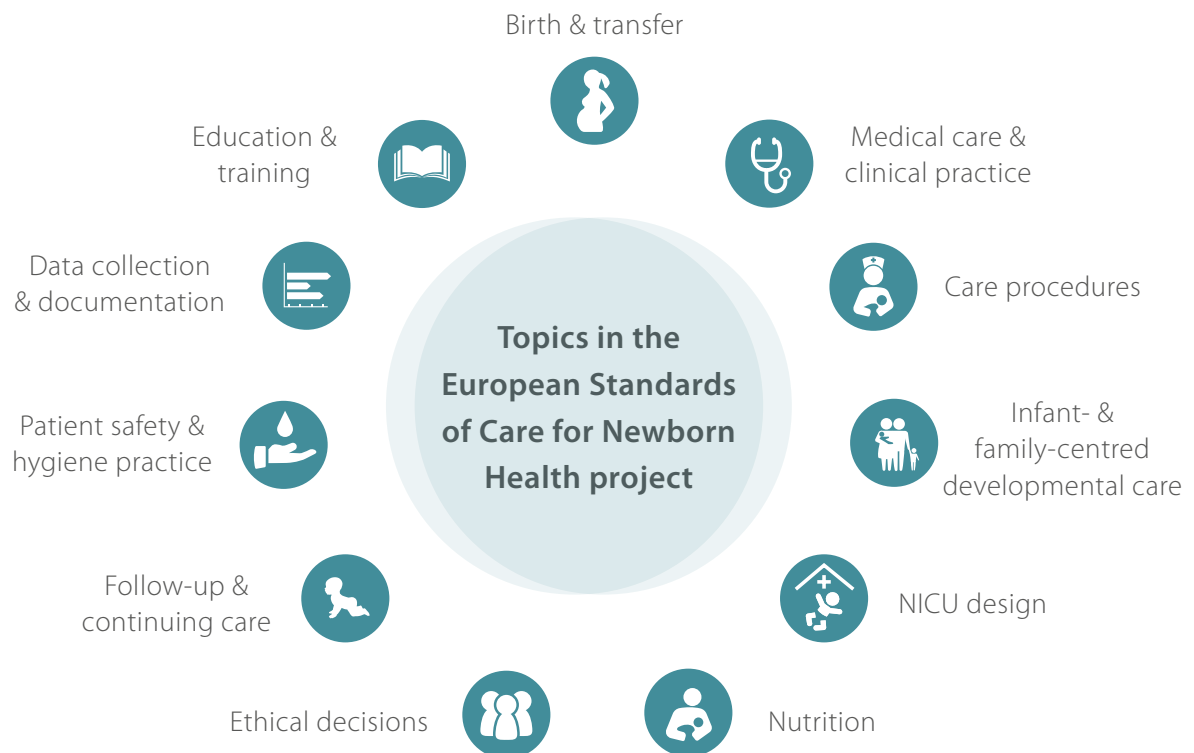


## About the European Standards of Care for Newborn Health project

Initiated in 2014 in the European Parliament in Brussels, the European Standards of Care for Newborn Health project aims to address the disparities in provision and quality of care existing in Europe by developing reference standards, which are covering the most important topics associated with preterm birth and neonatal morbidity. About 220 professionals, parent representatives, third party advisors, and industry specialists from more than 30 countries have come together to develop European reference standards of care for newborn health, with focus on the treatment and care of preterm and ill babies in hospital and as they grow up. These European standards are intended to be used as a source for a national development of respective binding and implemented guidelines, protocols, or laws (depending on the local situation).

In order to cover the complexity of neonatal care, 11 overarching topics were identified. Within each topic, single issues for standardisation were selected and further topics are continuously being defined. Standards start with topics around birth and transfer and continue until well after discharge into early childhood. Even difficult topics like ethical decision-making and palliative care are addressed in one topic expert group. In total, 96 standards were developed during the initial standard development phase and were launched in the European Parliament in Brussels in November 2018.

### The 11 Topic Expert Groups



The European Standards of Care for Newborn Health have been developed to:

- Overcome disparities in in-patient care and improve patient health outcomes all around Europe and beyond
- Drive the mind change for evidence-based healthcare delivery in the field of neonatology
- Create a policy and clinical practice environment that ensures optimal use of standards of care for newborn health, adapted to the local necessities as well as optimal access to prevention, diagnosis, treatment and care for every pregnant woman and preterm or ill babies

### Why is this project so unique?

The European Standards of Care for Newborn Health project stands out, due to several facts:

- It will promote **equitable and high levels of care for preterm and ill babies** throughout Europe by a **systematic approach** in terms of a multi-stakeholder involvement from scratch
- The **involvement of patient (parent) organisations** in every step of the standard development process
- The **broadness of topics**
- A **multi-level dissemination strategy**

### Awards and recognitions

As a result of her longstanding commitment in newborn and maternal health, especially for pushing the standards forward, Silke Mader became an Ashoka fellow in 2015. In 2017, the standards project was awarded one of the most innovative 'Landmarks 2017' by the initiative Germany – Land of Ideas.

In 2016, the project was mentioned in an Editorial by THE LANCET entitled 'The unfinished agenda of preterm birth'<sup>8</sup>, and in parallel to the launch of the standards, THE LANCET Child & Adolescent Health published an editorial 'Putting the family at the centre of newborn health'<sup>9</sup>. Several further publications are continuously referring to the newly developed standards. You can find a list of all articles citing and referring to the standards on the project's website: [www.newborn-health-standards.org/project/publications](http://www.newborn-health-standards.org/project/publications).



<sup>8</sup>'The Unfinished Agenda of Preterm Births'. The Lancet. 2016; 388 (12);

[www.thelancet.com/journals/lancet/article/PIIS0140-6736%2816%2932170-5/fulltext](http://www.thelancet.com/journals/lancet/article/PIIS0140-6736%2816%2932170-5/fulltext); Accessed August 2019.

<sup>9</sup>'Putting the Family at the Centre of Newborn Health'. [www.thelancet.com/journals/lanchi/article/PIIS2352-4642%2818%2930369-9/fulltext](http://www.thelancet.com/journals/lanchi/article/PIIS2352-4642%2818%2930369-9/fulltext).





## NOTE

In order to prepare yourself for any questions politicians and other stakeholders might have, get as many details as possible about the project and prepare possible new website content as a source of reference and up-to-date information. You may also want to share the information with your national politicians or other stakeholders. For further input have a look at chapter [Communication: Website](#) and chapter [Materials](#).

## The standard template

A specific template in a harmonised format and structure was created by the Chair Committee for the standard development process and provided to all authors.



## NOTE

Get familiar with the standard template to:

- Understand the content and the structure
- Find information easier and faster
- Be able to explain the standards to other stakeholders

**The statement of standard summarises the standard in only one sentence and the standard per se can be found in the table called 'Components of the standard'.**

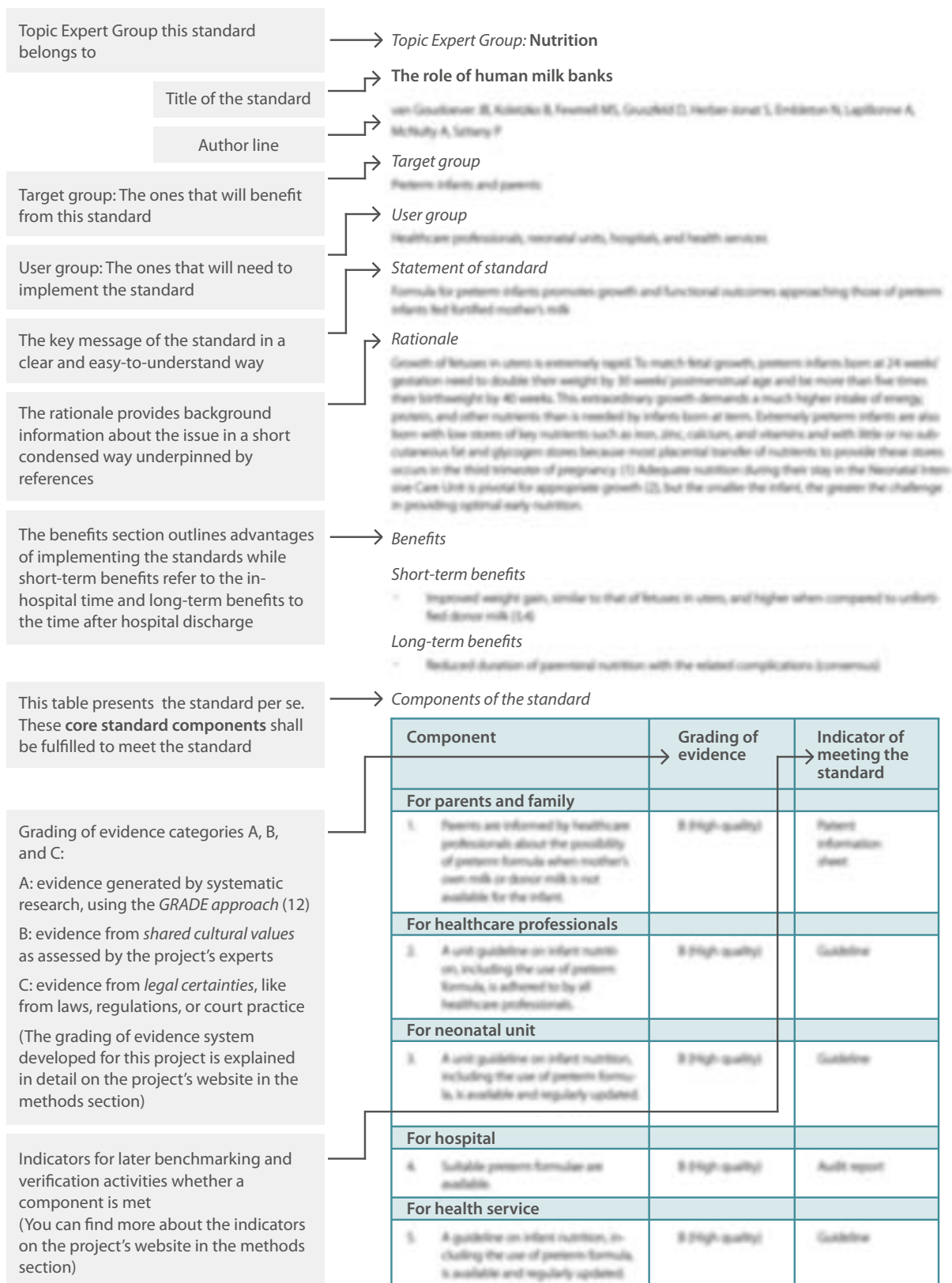


## Caution:

If you would like to translate the standards, please see chapter [Materials: How to use EFCNI's materials](#).

## The standard template

To facilitate a harmonised format and structure of the standards, a specific template was created by the Chair Committee for the standard development process.



## The standard template

Where to go – further development of care

Further development	Grading of evidence
<b>For parents and family</b>	
• Parents are verbally informed by healthcare professionals.	B (High quality)
<b>For healthcare professionals</b>	
• Develop and implement a guideline on infant nutrition.	B (Low quality)
<b>For neonatal unit</b>	
• N/A	B (High quality)
<b>For hospital</b>	
• Develop and implement a guideline on infant nutrition, including	B (High quality)
<b>For health service</b>	
• Support research on preterm formula to improve health.	B (High quality)

If hospitals already meet all core components of the standard, this table provides additional aspirational targets for further development; these are not part of the standard per se

The standards of this project represent a high level of care. For those hospitals where the components or some of the components seem to be beyond the current levels of care, the table 'Getting started' introduces initial steps that can be easily and immediately taken along a path towards meeting the components of the standard one day; these are not part of the standard per se

Getting started

<b>Initial steps</b>
<b>For parents and family</b>
• Parents are verbally informed by healthcare professionals about the possibility of
<b>For healthcare professionals</b>
• Attend training on infant nutrition, including the use of preterm formula.
<b>For neonatal unit</b>
• Develop and implement a guideline on infant nutrition, including the use of preterm.
<b>For hospital</b>
• Support healthcare professionals to participate in training on infant.
<b>For health service</b>
• Develop and implement a guideline on infant nutrition, including the use of preterm.

Additional information can be given in the 'Description' section of the template

The 'Source' section shows the scientific evidence behind the standard

All standards are first launched in November 2018. In case of revisions, the number of edition will increase, and the new release date will be displayed here

Description

Growth of fetuses in utero is extremely rapid. To match fetal growth, preterm infants born at 24 weeks' gestation need to double their weight by 30 weeks' postmenstrual age and be more than five times their birthweight by 40 weeks.

Source

1. Agopian A, Alomari A, Cornwell L, De Cunto M, Demerouti E, Dora T, et al. Breastfeeding Supply for Preterm Infants: Consensus from the European Society of Paediatric Gastroenterology, Hepatology and Nutrition Committee on Nutrition. *J Pediatr Gastroenterol Nutr*. 2015;60(2):285-91.
2. Day ML, Kennedy K, Costelloe K, Kragh T, Gifford ML, Roberts D, et al. Fetal and growth in preterm infants and later health outcomes: a systematic review. *Arch Pediatr Adolesc Med*. 2015;169(10):1076-85.

First edition, November 2018

Lifecycle

5 years/first revision: 2023

Recommended citation

EPON, van Goudswaam JB, Kuisma E et al, European Standards of Care for Neonatal Health: The role of preterm formula, 2018

The recommended citation of each standard

The standard will be considered for review latest at this time point. The lifecycle of each standard can be three, five, or ten years

### Supported by numerous healthcare societies and parent organisations

Over 170 healthcare societies and parent organisations, mainly from Europe, but also from the US, Canada, Australia, and Africa have declared their support for the developed standards and the Call to Action for Newborn Health in Europe (status: September 2019).

Please find an overview of all supporting healthcare societies and parent organisations here:

**[www.newborn-health-standards.org/project/partners/healthcare-societies](http://www.newborn-health-standards.org/project/partners/healthcare-societies).**



#### NOTE

You miss one of your collaborators among the supporters?  
In this case, please get in contact with us at **[standards@efcni.org](mailto:standards@efcni.org)**,  
as further organisations are cordially invited to join the line of  
supporters.

#### Supporting international parent organisations





# Statements of standards per Topic Expert Group

Each Topic Expert group (TEG) has developed several standards. With almost 100 standards in total, it can be difficult to keep an overview. If you downloaded all standards and compiled them into one comprehensive document, you would get a document of more than 600 pages. In order to get an overview of which standards are elaborated in that respective TEG, we recommend looking at the statements of standards of each TEG in the first step. The statement of standard is the key message of a standard and summarises the standard in a clear and easy-to-understand way (for more information, please see this chapter: [The standard template](#)).

The collection of all statements of standard per one TEG can also be used to raise awareness on a whole TEG, e.g. in social media graphics, PowerPoint presentations or on roll-ups. Follow this link to find all social media graphics with the statements of standard per TEG: [www.newborn-health-standards.org/downloads](http://www.newborn-health-standards.org/downloads). If you are interested in the roll-ups, for your own event, please contact us at ([standards@efcni.org](mailto:standards@efcni.org)).





Furthermore, different social media graphics were created using one single statement of standard in order to raise awareness to one specific standard topic.



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If you would like to translate the statements of standards, please see chapter [Materials: How to use EFCNI's materials](#). Special attention needs to be taken when translating the statements of standards, as the translation of these sentences without knowing the complete standards can be tricky.

## FAQs

You have any questions about the European Standards of Care for Newborn Health project? Maybe someone else has asked the same question already, so please check out the frequently asked questions section on our project website:

**[www.newborn-health-standards.org/call-to-action/faq](http://www.newborn-health-standards.org/call-to-action/faq).**

If you can't find what you are looking for, please do not hesitate to contact us via **[standards@efcni.org](mailto:standards@efcni.org)**, we are happy to help.



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## CHAPTER I Background information



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CHAPTER

# How to get started



# How to get started

## Overview

- Stakeholder mapping
- A guide for stakeholder mapping
- Building up a network in the field of care for preterm and ill babies
- Key negotiation skills
- Organising an expert meeting
- Different types of expert meetings

This chapter contains first critical steps for the implementation of the European Standards of Care for Newborn Health – in the following ‘the standards’. Building a national network and the identification of key stakeholders are one of the most important first steps, as networking can be a highly effective strategy of drawing attention to a particular policy issue that has either been ignored or deemed too insignificant to be properly addressed by policymakers or the general public. By working together, stakeholders with a variety of particular interests that all fall under an overarching theme, can be highly successful in achieving their individual aims.

As you work towards the implementation of the standards in your country, the first step within this implementation process is to get an overview on the status of your country in regards of newborn health and what the most urgent areas are that need to be tackled. This can be done in an expert meeting for example, where all relevant experts from different professions come together to discuss a common topic. For information and guidance on how to do research on health topics, please consult chapter [Background information: Data and supporting evidence](#).

Consulting this toolkit, you will be able to:

- Identify the key stakeholders who need to be involved when impelling clinical and policy changes for preterm and ill babies
- Provide a roadmap on how best to identify these groups or individuals
- Build a broad and active network of interested individuals and organisations with the common goal of improving care of preterm and ill babies
- Host an expert meeting on a specific health topic for the implementation of the standards in your country

## Stakeholder mapping

To affect the greatest change in improving and elevating the priority of public policy and clinical practice for preterm and critical infant care, an active national network of advocates is needed to increase the voice of preterm and ill babies. This means reaching out to new stakeholders, individuals, and organisations with whom you usually may not, or not yet, have had collaborations.

### What is a stakeholder?

- Someone who has an interest (a stake) in a certain topic
- A group of people directly or indirectly affected by a topic
- A person, an institution, a government, or a company, etc.



### NOTE





### NOTE

Please keep in mind that a stakeholder map needs to be created very specifically for each topic. In a topic like parenteral nutrition for instance, you will for sure include pharmacists in your stakeholder map who are responsible for compounding the nutrition, but also lactation specialists who are important to wean the child from parenteral nutrition. In other topics, like screening for retinopathy of prematurity, a lactation consultant is usually not needed, but an ophthalmologist instead. So define your stakeholders carefully depending on the respective topic!

## A guide for stakeholder mapping

In the process for mapping key stakeholders for your specific health topic, you have to think broadly and creatively about individuals and/or organisations who could be interested in your topic, their influence on the environment for this topic, and their priorities. Key to this approach is bringing together a strong group of partners and to support them become powerful advocates for prematurity issues:

Assess existing stakeholder relationships – think of everybody in your network who might be interested in the topic and is a potential influencing person.



Identify potential new stakeholders in the respective field – think broad and also think about people in your network who can create connections to these new stakeholders.



Prioritise key stakeholders – think who can make the biggest impact in the community.

Assess your existing relationships with stakeholders that might have a significant influence on policies affecting newborn health. This should not be a time-consuming task but help you to get a good overview and to estimate the strength of your existing network and where new contacts might be helpful and necessary. For assessing your existing stakeholders see the Excel worksheet template to capture existing and new stakeholder contacts (see [Appendix: Stakeholder mapping](#)).





## NOTE

Identify key stakeholders and also key opinion leaders in the topic you have chosen. When you have them on board, it helps you to get traction for your topic in the long run. **Also, think about involving stakeholders that might not share your opinion.** It is better to have them with you from the very beginning, as they are probably not alone with their opinion. And if you succeed in convincing them, they will help you to foster the topic!



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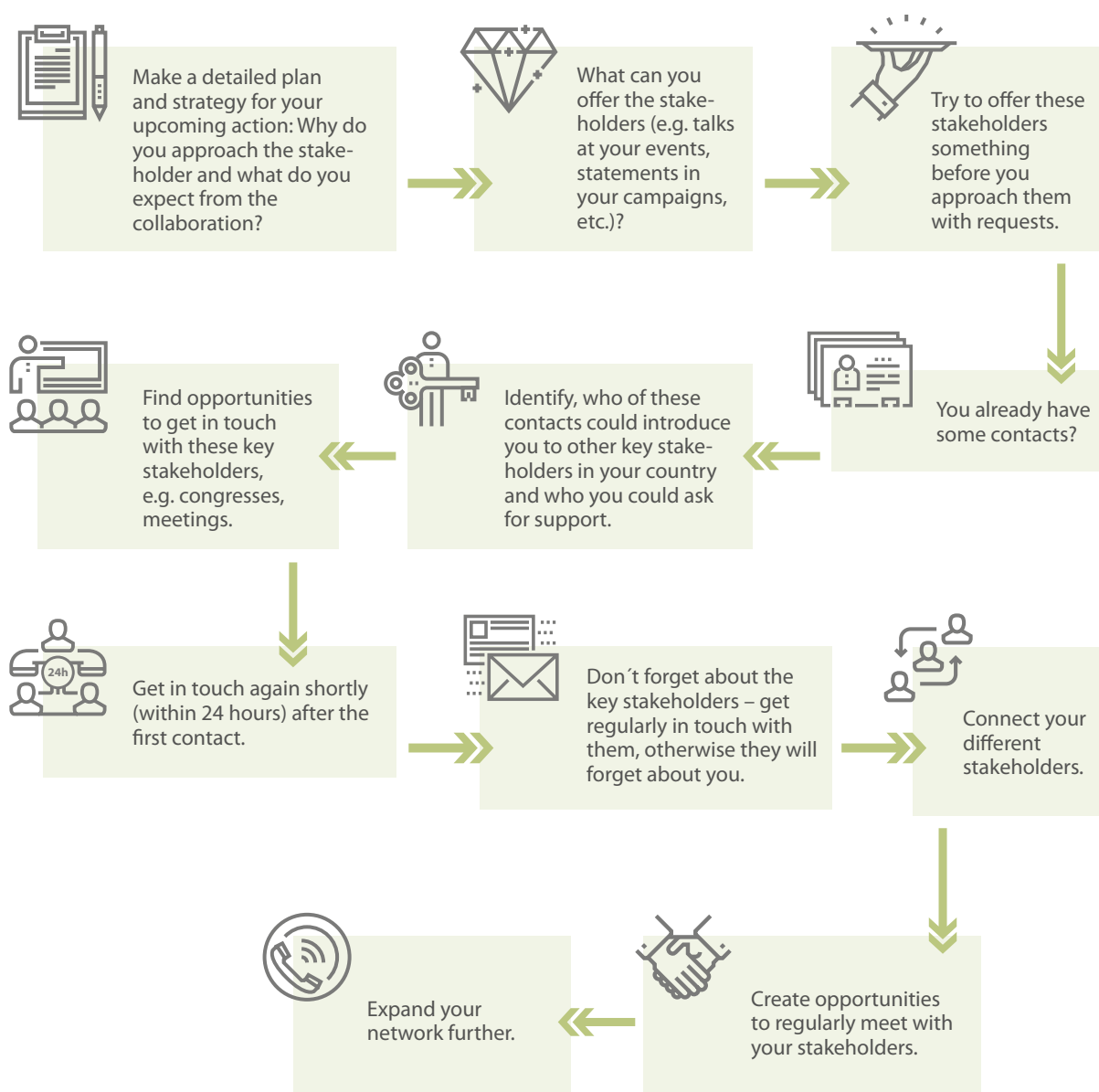


## NOTE

Stakeholder mapping is a quite long process, but the key for successful advocacy work and basis for the success of your plans! Within this process, it is very important to not forget any key stakeholder.

## Building up a network in the field of care for preterm and ill babies

Building up a network from scratch is not an easy task. For sure your organisation already has several contacts to different people/organisations related to preterm birth. Yet, if you should start from the very beginning, then ask the doctors who treated you and your baby as a starting point. They might be able to connect you with other healthcare professionals or organisations. As soon as you have established certain connections, follow the steps in this flowchart to build up a powerful regional and national network in the field of preterm birth.





## Key negotiation skills

Not everyone you identified as a stakeholder for newborn health might be on the same page with you from the start. Sometimes it will take time and skilled reasoning to convince others to support your cause and to realise that you share the same interests and have the same goal. Therefore, it is key to be prepared for a meeting and the negotiating process, especially, if you are not entirely familiar with your discussion partner.

### The five stages of a successful negotiation framework



#### 1. Preparation

- Identify potential value for the stakeholder you want to reach
- Begin to understand interests and BATNAs (Best Alternatives to a Negotiated Agreement) of yourself and your negotiation partner
- Develop fact-base information for your negotiation

1

#### 2. Information exchange and validation

- Discover and create value for the stakeholder you want to reach
- Assess interests and BATNAs of yourself and your negotiation partner
- Build rapport and trust with your negotiation partner

2

#### 3. Bargaining

- Create and distribute value for your negotiation partner
- Address interests, issues, and needs of yourself and your negotiation partner
- Make and manage concessions

3

#### 4. Conclude

- Capture value for your negotiation partner
- Confirm interests that have been met during the negotiation
- Summarise results of your negotiation
- Show appreciation to your negotiation partner

4

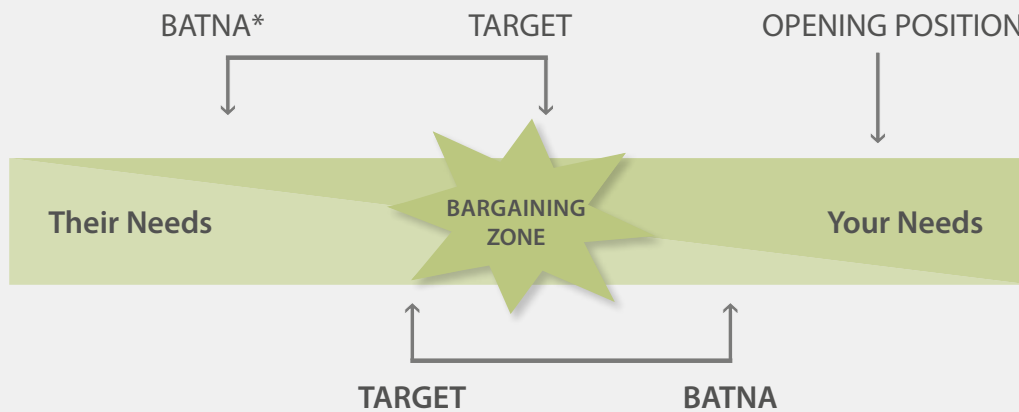
#### 5. Execution

- Expand value for your negotiation partner
- Address changing interests & future BATNAs for you and your negotiation partner
- Strengthen relationship with your stakeholder/negotiation partner

5

**What is BATNA?** The Best Alternatives to a Negotiated Agreement (BATNA) is your best alternative plan if the negotiated agreement will not be reached.

### The challenge of being successful



\*BATNA: Best Alternatives to a Negotiated Agreement



Negotiating requires a certain skill-set but don't be intimidated in case you cannot yet look back on long-term experiences in negotiating. These skills can be learnt and you will develop a routine in negotiating over time. Here is a collection of some useful skills that will help you to take on a confident and competent role in negotiations.

### **Know your BATNAs (Best Alternatives to a Negotiated Agreement)**

Know your needs and interests.

- ★ Prepare! Identify your most desirable outcomes, goals, least acceptable agreements, and BATNAs

Know the needs and interests of your negotiating partner.

- ★ Ask your negotiation partner which needs and interests are important for him/her
- ★ Ask other stakeholders who are experts in the specific field about potential needs and interests of your negotiation partner
- ★ Search online for information about your negotiation partner and his/her institution

### **Analyse your counterpart**

What body signs does your negotiation partner show you, or wants to hide?

### **Be persuasive**

Being persuasive and able to influence others verbally and nonverbally helps a lot.

- ★ Develop a 'Question and Answers (Q&A)' document to be prepared for discussions and arguments
- ★ Use questions which are interesting for your negotiation partner
- ★ Strengthen your arguments and messages nonverbally with a positive body language, e.g. a negative and reserved body language (e.g. crossed arms) will not strengthen your positive argumentation

### **Stay professional and in control of your emotions**

Shouting or crying never helps you to be taken seriously; additionally, you maybe think then irrational which results in losing negotiations. Whenever you find yourself being very emotional, you can shortly share your feeling with your negotiation partner, e.g. that you are an affected parent or deeply involved as a healthcare expert. That helps others to understand and respect your reaction in a specific situation.

### **Listen to your counterpart**

Careful listening and observing can help you to use every opportunity and to understand your negotiation partner.

- ★ Active listening means to give your negotiation partner feedback that indicates you understand the messages, e.g. smile and eye contact, lean in, nod, take notes
- ★ If you don't understand a question, medical content or you can't follow the discussion, don't hesitate to ask for more information and explanation to be able to understand and to join the discussion

### **Practice problem-solving skills**

Identification of a problem and being able to solve it is extremely important.

- ★ Speak openly about your identified problems or weaknesses and show and explain transparently your potential solutions

### **Practice your communication skills and body language**

Clear and effective communication helps to succeed in business negotiations. It is also very important to practice and control your own body language.

- ★ Reflect your body language beforehand (e.g. posture: where are your shoulders?, gesture: what are you doing with your hands?)
- ★ Practice your communication skills and body language in front of the mirror or family members and friends
- ★ If possible, attend a training course on communication skills and body language

### **Stay patient**

Don't push too much forward, as this often fires back.

- ★ In case the solutions or the desired goal will not be achieved straightaway, arrange a new meeting with your negotiation partner or hold on to minimum goals
- ★ Please keep in mind that solutions and changes need some time

## Organising an expert meeting

A meeting with all relevant experts about a standard topic is a first opportunity to take action in implementing the standards in your country. When planning your expert meeting, carefully consider the following points beforehand to make it a success.

### Objectives



**What do you want to achieve with your expert meeting?**

First of all, define your objectives. Possible objectives of your expert meeting could be to:

- Highlight the importance of newborn health or a specific topic in your country/region
- Inform about the standards and raise awareness
- Prioritise/highlight needs in your country
- Promote and foster the implementation of the standards
- Discuss one specific standard topic
- Find a joint opinion on a certain topic
- Establish a national working group for different standard topics
- Define a strategic plan for the implementation of certain standards



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## Possible results



### What could be the result of your expert meeting?

Second, determine what you expect from the meeting. Possible results of an expert meeting could be to:

- Align on a joint statement, e.g. on a standard topic
- Publish a factsheet, e.g. about a standard topic
- Develop a position paper, e.g. about the need of standards on a national level
- Prepare a publication in a scientific journal, e.g. on an analysis about the current status of standards/or a specific standard topic on a national level
- Create a media strategy to raise awareness, e.g. on a standard topic
- Share the expert's view in a press release, e.g. on a standard topic
- Set up working groups for different standard topics
- Define and plan further action points



## Target group



### Whom do you want to invite for the expert meeting?

As part of the stakeholder mapping (see this chapter: [Stakeholder mapping](#)), you should identify those key stakeholders who are important for the identified health topic. Agree on the key experts in the topic/objective you have chosen and invite them to your meeting.



#### NOTE

Double-check if you have forgotten any group of key stakeholders or any key opinion leader in the topic you have chosen for the meeting.

Also think beyond existing relationships and advocates who have been spoken to you or engaged with you to date.

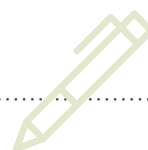
## Resources and timescales



### What resources do you have and what is the timeline for your expert meeting?

It is important to have an overview of the resources available before planning the meeting so that realistic goals can be achieved. There are different kinds of resources you have to keep in mind:

- **Financial resources:** to cover travel costs (if needed), honorary of experts, accommodation, venue, catering, design, or printing expenses, etc.
- **Human resources:** e.g. volunteers, free expert advice or employees of your organisation for preparation of the meeting and further follow-up (e.g. developing a position paper, publication, press release, campaign, or petition)
- **Time resources:** your own and your expert's time schedule, consider that key stakeholders are usually busy people and need to be invited well in advance
- **Structural resources:** e.g. support in logistics, benefits in kind, provision of an event location, pro bono agency services, etc.



#### NOTE

You would like to launch the outcome of the expert meeting, e.g. a position paper, a publication, etc., at a certain event? Then, start calculating backwards from the date of this event in order to know when you have to start preparing your expert meeting (e.g. inviting the experts, agree on a date and location, etc.).

If you have a lot of financial resources, you can hire an agency that supports you in the preparation of your event. Be aware, that the agency you work with needs your help and advice to be able to organise the event the way you want. Therefore, we recommend to plan everything hand in hand with your agency and also to control every step. This might also help you with difficulties in time resources. The same accounts of course vice versa: A lack of financial resources can be compensated by human power. But please be aware, certain costs (e.g. travel costs, rental of meeting rooms, etc.) may remain and cannot be compensated by human resources.

## Before the meeting



### What do you have to organise before the meeting?

Like a wedding or a birthday celebration, you would never expect your event to be a success without a good preparation. The same counts for your expert meeting. Make sure to:

- Identify participants and a moderator to lead through the meeting
- Think about starting your meeting with a keynote lecture by a key opinion leader who is well accepted in the community
- Identify and arrange the date and the venue in coordination with the stakeholders you are inviting to the meeting (e.g. via a doodle poll including three to four date proposals)
- Set up an agenda and coordinate it with the invited key opinion leader as well as the moderator
- Draft a meeting request letter (see [Appendix: Invitation letter template for attending an expert meeting/roundtable](#))
- Clarify (internally) if you need contracts between the participants and your organisation
- Send the meeting request letter together with the proposed agenda to all invitees timely
- Prepare additional materials and briefing information for the moderator and keynote speaker with suggested talking points
- Be well prepared: Gather as much information as possible about the respective topic (do literature research, follow ongoing discussions within your network and healthcare professionals, read available guidelines)
- Prepare the PowerPoint slides with the content as a basis for the discussions in the meeting (the one who is responsible for the protocol writes down all results)
- Plan enough time for discussions
- Share the final agenda as well as practical information (e.g. venue information, travel options) with the participants early in advance and ask if there is something missing what they would have expected
- Confirm catering arrangements with the venue (coffee breaks or working lunch are good opportunities for informal talk and exchange)
- Identify and determine people who will internally and externally follow-up to the meeting (e.g. write the final strategy/document/further action points) and discuss already during the meeting, whether everyone is fine with it
- Prepare all needed material (handouts, template for the meeting protocol, etc.) in advance



#### NOTE

Please note that this is not a complete list of tasks and possible preparations. In addition, there may be more or different things to keep in mind when organising an expert meeting. Please find an example of a checklist for organising an expert meeting in [Appendix: A checklist for the meeting organiser](#).



The following materials for the meeting can be developed in advance:

- Invitation letter, contracts, and agenda (see [Appendix: Invitation letter template for attending an expert meeting/roundtable](#))
- Information materials for the participants for preparation of the meeting
- Queries regarding food wishes and dietary specialties
- Template for the protocol (on the basis of the agenda)
- Thank you letter (see [Appendix: Thank you letter template for attending the expert meeting](#)) and evaluation survey



### NOTE

Take into account that some experts either might decline the invitation or cancel their participation at short notice due to other appointments. However, make sure to keep them in the loop. They might still be interested in the project and agree to participate as a reviewer, advisor, or other kind of supporter.



## During the meeting

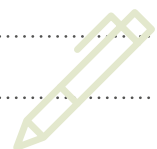


### What do you have to keep in mind during the meeting?

A smooth preparation of your meeting goes hand in hand with your work on-site, during the meeting. Here are some points to consider:

- Prepare the room and the venue (signpost the way to the meeting room, provide place sets for participants, make sure the equipment is in place and that technical equipment works)
- Welcome all participants and distribute personal name badges
- Explain the meeting rules and inform about the procedure and follow-up
- Introduce the moderator and let him/her lead the discussion
- Introduce the keynote speaker and the topic for the keynote lecture
- Stick to the agenda and discuss everything on there but also be prepared to plan enough time for discussions
- Document all the results transparently during the meeting (e.g. directly write down the results in your prepared PowerPoint slides via a beamer) so all participants can follow the discussion and everyone is up-to-date regarding the results of the discussions
- Discuss potential cooperation/supporting partners with the participants, e.g. healthcare societies, parent organisations, third parties (this will help you to build up your strong national network, see this chapter: [Building up a network in the field of preterm birth](#))
- Discuss potential dissemination plans and ask for support from the participants
- At the end of the meeting, summarise next steps and potential homework for the participants as well as the timeline with the deadlines, e.g. launch of a publication/scientific paper at the jENS congress 2021
- Develop the protocol, which is based on the agenda points, with all decisions made in the meeting

- .....
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## Follow-up of the meeting



### The expert meeting is over – what's next?

Honouring the time and expertise of your participating experts, we recommend considering these steps in following-up to your event:

- Send a thank you letter to all attendees thanking them for their time and contribution (within one week after the meeting) (see [Appendix: Thank you letter template for attending the expert meeting](#)).
- Share relevant documents and timetable for next steps/follow-up agreed (within one week after the meeting)
- If you develop a document summarising the outcome of the meeting, circulate the draft for feedback
- Actively ask participants for their feedback regarding the draft document
- Incorporate feedback to the draft document and circulate it to attendees for final comments
- Incorporate any final comments and circulate agreed document to all attendees
- Organise further steps (dependent on objectives/results of the expert meeting and what has been agreed on during the expert meeting)



### NOTE

Send out your thank you emails **within 24 hours** after the expert meeting. This will show that you are committed, organised, and will help you motivate the participants to support you in the next follow-up steps. These mailings can easily be prepared before the meeting (see [Appendix: Thank you letter template for attending the expert meeting](#)).

Keep everybody regularly updated (within one week after the meeting). If the preparation of the material etc. takes some time, inform the participants about the timeline and maybe about the changed timeframe, in which you will send out the documents for review.

## Evaluation of the meeting



**Did you achieve what you set out to do?**

It is important to assess and adapt your activities to ensure they are as effective as they can be. Thus, evaluation of your meeting can help you to identify areas for improvement and ultimately help you to realise your goals more efficiently:

- Organise a wrap-up meeting with your team involved in the organisation of the expert meeting and talk about what went well and what could be improved
- Were there any problems and could they be solved? Why did they happen and how could they be prevented in the future?
- After your meeting, ask your participants to evaluate the meeting, e.g. by distributing an evaluation sheet among your participants
- Alternatively, you can send out an evaluation survey to the participants after the expert meeting



## Different types of expert meetings

Depending on the topic, your resources, and your goals, there are different types of expert meetings you could carry out. In the following, you will find examples of different types of expert meetings, advice, and practical examples of what to consider in selecting the right format of expert meeting for your cause.

### Roundtable



#### What is a roundtable?

The expression 'roundtable' has been used since 1880: the term was coined from King Arthur's legendary roundtable, which he and his knights congregated. As its name suggests, the table has no head, implying that everyone who sits there has an equal status.

A roundtable thus is classified by having small group discussions (no more than 10-15 people, generally not open to the wider public), where **everybody on the table is seen equal**. The general purpose is to hold a close discussion and exploration of a specific topic, but the individual aim of a roundtable discussion varies in practice.

A roundtable is a useful instrument to:

- Bring different understandings of a problem together
- Identify gaps, needs, and opportunities in a country/region on a specific health topic
- Discuss and recommend practices and approaches to improve the situation
- Reach a consensus about an identified problem and a way towards solutions



**Practical example:****Expert roundtable of the Bulgarian parent organisation Our Premature Children Foundation (OPCF) in April 2019**

In April 2019, the Bulgarian parent organisation Our Premature Children Foundation (OPCF)/ Фондация Нашите недоносени деца (ФННД), which is a partner of EFCNI, organised a roundtable about the European Standards of Care for Newborn Health in Sofia, Bulgaria. The event marked the starting point for the development of a national programme for the follow-up care of children born preterm in Bulgaria from birth to 7 years of age.



© Our Premature Children Foundation (OPCF)

The standards on follow-up and continuing care served as a basis for discussion and the participants focused on how these standards could be adapted and implemented in Bulgaria. Furthermore, the information brochure about the European Standards of Care for Newborn Health by EFCNI\* was translated into Bulgarian particularly for this roundtable and was distributed among the national experts during the event.

Parent representatives, experts in the fields of neonatology, early childhood development, paediatrics, and medical law, as well as further key stakeholders discussed the current situation in the area of follow-up care of preterm and ill babies and formed a scientific advisory board. The meeting was characterised by a positive working atmosphere, a strong commitment to the topic, and the willingness of all participants – both parents as well as healthcare professionals – to understand each other's perspectives. Both parties actively contributed to the meeting and shared recommendations and challenges in their everyday work. As a result of the roundtable, the participating experts developed an action plan and the first national programme on the follow-up care of children born preterm in Bulgaria.

Shortly thereafter, the final document was handed over to the Bulgarian Ministry of Health, the Ministry of Social Policy, and the Ministry of Education for further political action. The project is among others supported by the Bulgarian Neonatology Association, the Bulgarian Paediatric Association and the office of the World Health Organization (WHO) in Bulgaria. Altogether, the roundtable was a very promising start for a long-term transformation of follow-up care for preterm born children in Bulgaria. From this initial spark, many further steps towards the implementation of the standards in the country will follow.

Please find more information on the website of Our Premature Children Foundation (OPCF) (in Bulgarian) at: [www.bit.ly/Our\\_Premature\\_Children\\_Foundation](http://www.bit.ly/Our_Premature_Children_Foundation).

\* The brochure is available at [www.newborn-health-standards.org/downloads](http://www.newborn-health-standards.org/downloads).

### Seminar



#### What is a seminar?

A seminar is an expert meeting with lectures by most/all experts with short question and answer sessions and a longer discussion round at the end.

A seminar is a useful instrument to:

- Stimulate a general information exchange on one topic or area
- Prepare for a follow-up action, e.g. discussion of a scientific paper on the topic
- Inform a group of people on a common topic
- Work on a common topic but wish to have input of experts on different sub-topics and facets of the topics

#### *Practical example:*

##### **Seminar of the Norwegian parent organisation Prematurforeningen in December 2018**

On the occasion of their 30th anniversary, the Norwegian parent organisation Prematurforeningen, a partner in the EFCNI network, chaired a seminar at Rikshospitalet, Oslo, as a national follow-up of the launch of the European Standards of Care for Newborn Health and the Call to Action for Newborn Health in Europe in Brussels.

About 15 experts in neonatology contributed to the well-received seminar. They offered a broad overview of care procedures in Norway and gave insights into recent achievements, the ongoing implementation and also pointed out, where improvements are still feasible. The experts also concluded that many clinical practices are referring to habits and not necessarily to evidence-based findings – a shift of mind and a willingness to allow changes is key if sustainable progress in neonatal care shall be realised.

The event was followed by a visit to the NICU ward of Drammen Hospital close to Oslo, so the previously discussed topics could actually be observed on-site.

Please find more information on the website of Prematurforeningen (in Norwegian) via: [www.bit.ly/Prematurforeningen](http://www.bit.ly/Prematurforeningen) and on the EFCNI website via [www.bit.ly/Prematurforeningen\\_implementation\\_standards](http://www.bit.ly/Prematurforeningen_implementation_standards).



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## Workshop



### What is a workshop?

A workshop is an expert meeting with a hands-on/practical part for the participants to be actively involved (e.g. practical training, exercises). Usually, a workshop has a narrow focus on one topic and works best if it is limited to a number of maximum 15-20 participants.

A workshop is a useful instrument to:

- Inform a group of people on a common (practical) topic
- Develop learning skills and train a group in certain topics, e.g. on how to put the standards into practice

### Practical example:



### Parent workshops on the European Standards of Care for Newborn Health project

Since 2016, EFCNI has organised and hosted workshops for parent organisations on the European Standards of Care for Newborn Health project. These workshops aim to give representatives of parent organisations the skills and tools to inform about the standards, to advocate their adaptation, and to push forward their national implementation in the respective countries of the participants. Through exercises and via practical training in these hands-on workshops, the participants learn about the standards and the best way to put them into practice and to achieve changes in their country. Participants learn how to do stakeholder mapping, how to organise a roundtable, why standards are needed and how to cooperate and work with healthcare professionals.



### Scientific event/congress



#### What is a scientific event/congress?

A scientific event/congress is a large meeting of scientific experts of a certain (research) field to learn about recent developments, present new data, and discuss findings and exchange with colleagues. It usually lasts between 2-5 days and consists of lectures, discussions, as well as oral and poster presentations.

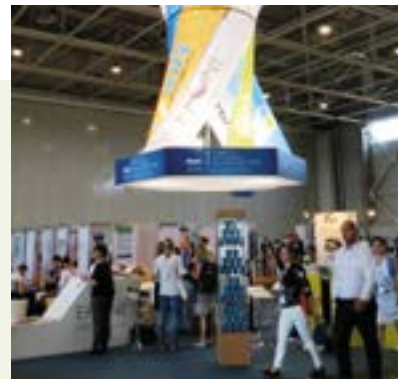
A scientific event/congress is a useful instrument to:

- Routinely (every year/every two years) have a large (international) scientific meeting
- Bring international and/or national experts together to exchange on specific as well as overarching 'hot topics' and state of the art research

#### Practical example:

The **congress of joint European Neonatal Societies (jENS)** is the first international neonatology congress where medical societies, scientists, healthcare professionals, and parent representatives form a partnership and contribute equally to the congress programme. It is also the joint biennial meeting of EFCNI (European Foundation for the Care of Newborn Infants), ESPR (European Society of Paediatric Research) and UENPS (Union of European Neonatal and Perinatal Societies). Since the launch of the congress in 2015, jENS has developed into an important congress with around 2,100 attendees. With an audience from all over Europe and overseas, jENS is an international congress, where neonatal physicians and nurses, paediatricians and parent representatives get together to discuss how neonatal care can be improved.

View more at: [www.efcni.org/jens](http://www.efcni.org/jens).





## Individual meetings with stakeholders



It is also possible to organise a meeting with individual stakeholders (e.g. one to three stakeholders). Thereby, it is important to ask the stakeholders for their opinion and also to involve them as much as possible in the process and your plans/project. Actively ask for their support within your activities/project, e.g. by approaching their networks. Depending on the size and scope of the meeting, most of the issues addressed in this chapter: **Organising a roundtable** apply to individual meetings as well.



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Furthermore, **you could be invited as a participant to an expert meeting** which is organised by another organisation or healthcare society to represent the patients' voice. When participating in such expert meetings, please keep in mind to:

- Respond to the invitation as quickly as possible
- Thank them for the invitation and the possibility to participate in the meeting
- Prepare yourself in advance (do some research about the topic, the organiser, and the participants)
- Be in time for the meeting
- Appreciate and respect the other participants
- Actively participate in the meeting

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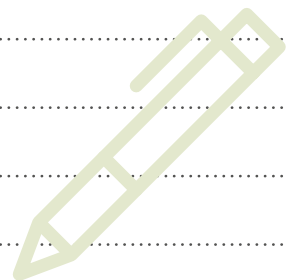
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For questions or queries, please contact: [standards@efcni.org](mailto:standards@efcni.org).



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CHAPTER

# Advocacy on EU and national level



# Advocacy on EU and national level

## Overview

- Advocacy work
- 10 step advocacy process
- Presentation of the standards for politicians
- A conversation guide for efficient meetings
- An instrument for your advocacy: The Call to Action for Newborn Health in Europe
- Set of arguments for Call to Action and the standards
- Message house method
- Summary: Advocacy in a nutshell
- Do's and Don'ts in advocacy work

Politicians are probably one of the first target groups that come to mind when planning to implement the European Standards of Care for Newborn Health – in the following ‘the standards’ – in your country. In this chapter, you will learn more about advocacy work both on a European Union (EU) as well as on a national level and how to make your cause a priority in the political agenda.

To create an impact and to create change, there is a need for having a solid two-way dialogue in place. On the one hand it is essential to understand the local country dynamics and local pressures. This can only be done at a national level. On the other hand, one also has to provide an above country European perspective to highlight commonality and increase priority. You must bear all this in mind when preparing and planning your advocacy work. Another important aspect to keep in mind is that it is of utmost importance to work together with all stakeholders involved in the care of preterm and ill babies (e.g. neonatologists, paediatricians, nurses, midwives, parent representatives, hospitals, and insurances). Only if all of these stakeholders work together, advocacy work can be efficient. This aspect also reflects the general idea of the European Standards of Care for Newborn Health project – to involve a multidisciplinary team of experts and parent representatives.

Having a clear plan is key when approaching politicians, in order to appear as a serious and professional organisation, and to achieve your goals for change. In the following, you will learn more about how to plan your advocacy activities, how to build up a solid argumentation, and steps to consider when contacting your national politicians.

Consulting this toolkit, you will be able to:

- Understand advocacy work on EU and national level
- Clearly present the standards to politicians
- Internalise a conversation guide for discussions with diverse stakeholders
- Explain the Call to Action for Newborn Health in Europe and how it supports the implementation of the standards
- Have arguments about the standards at hand
- Create strong messages about the standards targeted to the stakeholders you want to reach out to

## Advocacy work

Your aim is to ensure that preterm and ill babies in Europe and beyond receive the best possible care?

Advocacy work is fundamental to have the views and wishes of these vulnerable patients genuinely considered when decisions are being made about their lives. As a patient representative or healthcare professional, you are also an advocate to have their voice heard on issues that are important to them.



### NOTE

#### What is advocacy?

- A process through which an individual or a group (e.g. a patient organisation or healthcare professional society) attempts to change political, economic, and social decision-making or attitudes
- It is often accompanied by evidence, arguments etc. to educate the audience how and why the requested change should happen

## Why to do advocacy work?

At current stage, there is a lack of awareness and action at all policy levels for maternal and newborn health, particularly for the potential risks and challenges of preterm and ill babies and their families. It is thus important to put maternal and newborn health, especially the health of preterm and ill babies, on the political agenda of Europe, but also on the national agendas. Influencing political decision-making with your advocacy work is indispensable as practical support work and self-help alone are unlikely to produce sustained improvements for pregnant women, preterm or ill babies and their families. Moreover, advocacy can also benefit further aspects of your organisation's work, for example increase your visibility, fundraising opportunities, etc. Through regular advocacy work, your organisation will be increasingly recognised as a serious player among opinion makers in policy, healthcare and among other experts, as well as the wider public.

Before you start your advocacy work, it is key to first analyse the situation in your country and to localise your strategy. Always keep in mind that there are several levels of advocacy you have to approach – depending on your concern and the type of change you want to achieve.

### Levels of advocacy

Organising and delivering health services and medical care in Europe is mainly a country issue or a matter of the respective federal state. However, the European Union (EU) complements the national policies and carries out health-related activities to protect and promote public health across the EU, to support the cooperation between the member states and/or to overcome shared health challenges or inequities between the countries. Typical EU activities or campaigns include for example major diseases such as HIV/AIDS or cancer, communicable diseases, healthy lifestyles, or drug abuse. The legal basis for laws on recognition of professional qualifications allowing healthcare professionals to work in any European country is set by the EU single market rules.

The EU Parliament as a decision-making body (in co-decision with the EU Council) has been strengthened with regard to health, environment, food safety, and consumer protection topics. The EU Commission launches legislative initiatives (e.g. for medical devices or parental leave) with standardised consultation procedures and in dialogue with civil society and experts. To implement the EU Health Strategy, the Commission uses the EU Health Programmes which fund projects to improve public health, to prevent illnesses, and to eliminate threats to physical and mental health in European countries. The role played by EU agencies such as the European Medicine Agency (EMA) has been enhanced over the last years.

Therefore, advocacy work needs to be done both at European, national, and at regional/local level.



#### NOTE

It is important to speak to EU politicians AND your national or regional politicians and other decision makers as well as to key opinion leaders about all issues that have an impact on your country.

### 10 step advocacy process

#### How does advocacy work look like in practice?

To plan your activities, take a closer look at the advocacy process. It can be split up into 10 key steps that may have to be repeated all over again.




#### NOTE

The European Standards of Care for Newborn Health project was set up as an interdisciplinary project bringing together all stakeholders involved in the care of preterm and ill babies. This approach should be reflected again in advocacy work and in general in pushing the standards forwards in your country! Only together we are strong and can make an impact in the care of preterm and ill babies.

# 10 step advocacy process





## Step 1 – Understand the problem

First of all, it's important to **fully understand the situation** regarding preterm birth in your country. To get an overview about the current situation (e.g. preterm birth rates, structure and organisation of treatment, current gaps), please see chapter [Background information: Data and supporting evidence base](#). To **understand the context** and how laws/guidelines/standards/recommendations are made in your country, you can answer yourself the following questions with regard to the implementation of the standards in your country. Please note, that these are examples and this list can be completed and adapted to your country's needs.

### Example for the standards:

*Do we have national guidelines, recommendations, and/or standards in newborn health especially for preterm and ill babies?*

*Who is responsible for the development of those in my country?*

*Which standards are already implemented in my country, which ones need an update or need to be developed?*

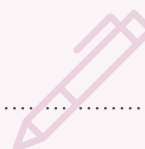
*How could the process to implement the standards work in my country?*

*How can I/my organisation be involved?*

*Who else needs to be part of this process?*

.....

.....



## Step 2 – Define your aim

After understanding the situation, **the aim** of the advocacy process needs to be defined.

### Example for the standards:

*What do you want to achieve in your country regarding the standards?*

*What standards do you want to start with, depending on the most pressing needs in your country?*

*How many standards should be implemented within the next 5 years in your country?*





## NOTE

This cannot be done by one person or organisation alone: try to set up an interdisciplinary working group/focus group to achieve an understanding about aims and priorities for your country. Make sure to also consider contradictory point of views and to agree on a common course of action.



## Step 3 – Know whom you talk to

At this stage you have to define **whom you need to talk to** in order to improve the situation for preterm and ill babies in your country – look for influential stakeholders and allies (see chapter [How to get started: Stakeholder mapping](#)).

This could be, for example, policy makers in national ministries (e.g. health, justice or social affairs) and the parliament, neonatologists, paediatricians, obstetricians, midwives and their societies, universities, or patient organisations for preterm and ill babies.



## NOTE

Keep in mind to identify and seek exchange also with those stakeholders who might have a diverging or even contrary approach to your topic!

Keep in mind that politicians are very powerful and can change several things in your country. But there are certain topics, they are not responsible for. Take Germany as an example: to change the situation about parental leave, politicians are the right people to talk to. But to change the educational system for medical doctors, you would need to talk to the German Medical Association, as this is a topic they are responsible for.



## Step 4 – Develop 'catchy' messages

Now that you have identified relevant stakeholders and for your topic relevant politicians, it is important to immediately catch their attention. They are most likely very busy people and receive many requests to the most diverse topics. Therefore, you need to **send out the right messages**. Especially policy makers want to hear solutions, not only problems. Adapt your message to the audience you are approaching. Think about from which angle you should tell your message and outline your cause, e.g. from a national or even local angle, and reinforce your argumentation with numbers and facts (see this chapter: [Message house method](#)), e.g.:

*Preterm babies around Europe don't have an equal start in life, as care varies between countries, regions, and even hospitals. (1)*

### References

1. Keller M, Saugstad OD, van Steenbrugge G, Mader S, Thiele N. Caring for Tomorrow. EFCNI White Paper on Maternal and Newborn Health and Aftercare Services [Internet]. European Foundation for the Care of Newborn Infants (EFCNI); 2011. Available from: [www.bit.ly/White\\_Paper\\_EFCNI](http://www.bit.ly/White_Paper_EFCNI)



NOTE

Know your sources in order to be a credible and transparent discussion partner. You find references for each standard topic at the end of every standard. These are very helpful to get more knowledge and to be a well-informed discussion partner!



## Step 5 – Identify possibilities to engage with your stakeholders

There are probably **numerous ways to engage** with your target stakeholders. The right timing for your input is important: be informed about good moments for informal and formal processes, so called policy windows. Politicians or government officials are more likely to pay attention to your message if you frame it within the context of an upcoming policy decision, major summit, or election, etc. Observing the field and keeping an advocacy calendar with relevant events and deadlines may help to grasp the right moments and deliver the right message to the right person at the right time.

### Example for the standards:

*A celebration for World Prematurity Day or another health/awareness day celebrated in your country might be a good idea to invite and interact with a politician. During this interaction you might also find time to discuss with him/her your issues or get the opportunity for a longer meeting.*

## Step 6 – Identify suitable tools



Not every tool might be useful for every stakeholder. So **pick the right tool** to reach your audience. In the following graphic you will find some examples:



Letters



Petitions



Policy  
briefs



Phone  
calls



Emails



News-  
papers



Radio and  
TV



Meetings



Posters



Holding an  
advocacy  
day



Campaigns



One-to-one  
meetings

## Step 7 – Set up a plan to engage with politicians



When you **set up your plan to engage** with politicians, have in mind that you want to build up a long-term relationship here. Work according to the motto 'Seed, grow, harvest'. Such a plan should already contain possible opportunities for engagement and contacts over a longer time. Also, include ideas of how you can support the politician in his or her work.

Do not expect too much from a single meeting. Plan a series of (regular) meetings and opportunities to interact instead.



### NOTE

You could for example invite the politician to give a quote for a press release or your newsletter, to give the keynote lecture at your event or write greetings in one of your publications. There are several different ways which you could use to promote that the politician is actively involved in your organisation. It is also important to send him or her regular updates on what is going on: inform them about relevant news and success stories which their support enabled, and of course thank them! See and be seen – that's the way to go!

## Step 8 – Engage with them



Finally, it is time to **engage!** Be prepared, know the position of your counterpart, have your messages ready, what can you offer? Have ideas in mind of what the politician can do for you and only come up with topics that he or she is responsible for.

Please have a look at this chapter: [A conversation guide for efficient meetings](#), where you will learn about how to structure a conversation with a politician or other key stakeholders. When engaging with your (local) politician for the first time, we have some ideas for you - please see [Appendix: Introduction letter template for contacting a politician](#).

## Step 9 – Stay in contact and keep up the dialogue



After your first encounter, it is important that you **follow-up** immediately! This will show that you are trustworthy and a reliable partner for a proper partnership. But also **keep up the dialogue** continuously.

### Example for the standards:

*You could e.g. send a thank you letter together (see [Appendix: Thank you letter template for attending an expert meeting](#)) with a short summary of what has been discussed, agreed next steps, and use this opportunity to invite the policy maker to another event. Or maybe there are still open questions after your meeting that you could answer by email.*

## Step 10 – Evaluate your efforts and outcomes



You for sure would like to know if all your efforts have been worth it. Therefore, **evaluate your efforts and the outcomes** that were achieved. Of course a change in policy, or even better in outcome numbers would be the best outcome to achieve. But keep in mind that these changes can take several years. In order to show small successes, it is important to also evaluate small steps on the way to a change of policy or outcomes. There are steps in between that you can evaluate.

*How often did you talk to a certain person? Did you identify shared interests?  
Did you agree on certain goals or next steps? Were there any interactions with other stakeholders?  
Were agreed steps implemented?*

As change often takes place over a longer time span, measuring your advocacy success is challenging. Therefore, choose simple indicators, allowing you to monitor and measure your achievements. Ask yourself for example:

- *Can you rate the likelihood of (partial) success?*
- *Can you identify concrete steps of success on the way towards your overall goal?*
- *What might be changing along the way and may force you to change tactics or revise your overall goal?*

## Presentation of the standards for politicians

The implementation of most standards doesn't cost a lot of money, but goes along with a mind change of the involved stakeholders which usually is a long-term process. Other standards are definitely costly. In the end, someone needs to provide funding for the implementation of the standards on a national basis. Additionally, in many cases the implementation of the standards might also require structural changes or legal adaptations. In most cases, you need to involve politicians to achieve your goals. To explain your concern, you will probably have to present the standards in front of politicians. Maybe you are invited to present the standards at your local and/or national parliament, a committee, or at another official political meeting?



### NOTE

Keep in mind that most politicians are no healthcare professionals and are obligated to always act in the best interest of the whole society, not only a specific group.

Therefore, it makes sense to:

- Explain all medical terms you use well
- Present the problem and underpin it with facts
- Talk about long-term effects of preterm birth and their effects on society
- Include health-economic aspects
- Show solutions: How can the standards help improve the situation?
- Identify one example to make it more transparent for the politician and his/her interest

To present the standards to politicians, download the PowerPoint presentation template at [www.newborn-health-standards.org/downloads](http://www.newborn-health-standards.org/downloads). Make sure that you always use the **latest version** of the template for your presentation as regular updates are provided on the website. Please note that the template is a general template and that you need to add national data and facts.

For further information about how to use the PowerPoint template provided by EFCNI see chapter [Materials: PowerPoint presentation template](#).

## A conversation guide for efficient meetings



### NOTE

This conversation guide provides you with some basic ideas how you can lead a meeting with different stakeholders like politicians, journalists, healthcare professionals, and other patient organisations.

The guide gives tips how you can structure your meeting and also works as a script of what you could actually say. Please adapt the italic parts in brackets [lorem ipsum] with your individual case to your country situation.

When preparing for your conversation, please consider the following aspects:



Think about possible difficult questions about your organisation's objectives, about your funding, and the actual situation in your country/region that you might be asked during the meeting



Prepare some Q&As (questions and answers) about your organisation that help you to always answer questions in the same way



Prepare some ideas of how the politician can support your cause keeping in mind what lies in his or her possibilities



Always try to get back to your key messages when you answer a question



If you do not know the correct answer, express this, and get back with the correct answer after the conversation/meeting e.g. via email or phone

## 1. Introduction



**'Thank you very much for accepting my meeting request and for taking the time to discuss about [topic, e.g. *Preterm birth and why we need standardisation of care*].'**

In case you are meeting for a second time: Mention any remarks you have and refresh the memory from a previous meeting.



## 2. Who are you and who do you represent?



*'My name is [name] and I represent the [name of your organisation and what kind of organisation this is, who do you represent?]. I am also personally affected as my child was born [preterm/with illnesses/...].'*



### NOTE

It is very important to be transparent about how your organisation is funded and about what you are doing. Therefore, prepare yourself to answer questions on how your industry partners influence your activities. Develop a code of practice and other transparency documents for your organisation and refer to them. Have a look at the EFCNI website ([www.efcni.org/transparency/](http://www.efcni.org/transparency/)) to see what these documents can look like!

Find out if there are transparency registers in your country and register with them. In addition, make sure that the work of your organisation is compliant with codices like the International Codex of Marketing of Breast-Milk Substitutes by the WHO.

## 3. What is preterm birth and what are the consequences?

Talk about definitions and numbers:



- 'A preterm birth is defined as a birth occurring before 37 weeks of gestation (normally a pregnancy lasts between 37 and 42 weeks).<sup>1</sup>
- There are about 15 million babies born preterm every year, worldwide. This is approximately 1 baby in 10. In [your country] [X]% of all life born babies are born preterm. Since 2010 the numbers were [rising/decreasing].<sup>2</sup>



### NOTE

European numbers can be found in the EURO-PERISTAT (see chapter **Background information: Excursus Euro-Peristat**). National numbers can be found at your health ministry or other statistical resources.

<sup>1</sup>World Health Organization. Preterm Birth. Available from: <https://www.who.int/news-room/fact-sheets/detail/preterm-birth>. Accessed August 14, 2019.

<sup>2</sup>Althabe F et al. World Health Organization. Born too soon: the global action report on preterm birth. 2012.

Available from: [www.who.int/pmnch/media/news/2012/201204\\_born\\_too\\_soon-report.pdf](http://www.who.int/pmnch/media/news/2012/201204_born_too_soon-report.pdf). Accessed August 14, 2019.

Talk about risk factors for preterm birth:



**'In several cases it is not known what exactly causes a preterm birth, but there are a number of risk factors that are known to be associated with preterm birth, like:**

- **Medical conditions, like infections, high blood pressure, underweight or obesity, as well as diabetes**
- **Lifestyle conditions, like alcohol consumption, smoking, drug use, high stress level, long working hours, lack of social support, and late or no prenatal care**
- **Demographic factors like being younger than 17 or older than 35 during pregnancy**
- **A low socio-economic status'**

Talk about the consequences a preterm birth might have on the baby, the family, and on the society as a whole:



- **'Preterm birth is worldwide the main cause of death in children under the age of five years**
- **Preterm born children are at a greater risk for developing short- and long-term health problems. The earlier a baby is born, the less developed its organs are, and therefore, these babies are more likely to have medical complications. For example cerebral palsy, learning issues, sensory problems, and respiratory diseases**
- **Many of these challenges do not only impact the baby, but also the family, as often at least one parent cannot go to work for a long while, and the costs of the long-term care also have a high impact on the society as a whole'**



#### NOTE

After showing clearly all the consequences a preterm birth can have, it is important to show that the implementation of the standards can improve the outcomes of preterm and ill babies and reduce the before mentioned consequences.

## 4. What are you requesting?

Adapt your request to the most pressing issues in your country, to what your counterpart might be interested in and always keep in mind what your counterpart is in charge of. Only request things that he or she is responsible for! In the following, you will find some ideas related to the standards:



- Ask for support of the implementation of the standards in [your country] along with the development of national guidelines (e.g. setting up a formal focus group for the local adaptation of the standards in your country, a regulation or law for the mandatory regular review of existing standards involving patient representatives, the set-up of a national register,... - think about the most important needs in your country)
- Address the lack of data collection and data availability in [your country] and request the set-up of data collection tools/register
- Address the need for enough specialists and continuous education and training of healthcare professionals and ask for obligatory, qualified trainings, better salary, ...
- Increase access to specialised and appropriate follow-up for preterm born children
- Increase social support for families affected by preterm birth through for example extended maternity and paternity leave or by financial support for parents and preterm babies

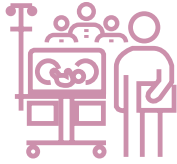


### NOTE

You can also have a look at the Call to Action for Newborn Health in Europe for more inspiration (see this chapter: [An instrument for your advocacy: The Call to Action for Newborn Health in Europe](#)). There are 14 demands that you can adapt for your country and discuss with your politicians.

## 5. What do you expect from your counterpart?

This very much depends on the background of the meeting. But be prepared to give your counterpart suggestions how they can support you.



- You might ask a politician to raise the issue in the Parliament
- You might want to invite him/her to one of your events
- You might want to invite him/her to visit a NICU, meet affected families and speak to healthcare professionals about their challenges
- You might want to ask for support in organising a joint political event

Also be prepared to express how you and your organisation might be able to support your counterpart.

## 6. Conclusion

You may end the conversation by making a 'final' summary on what you were just talking about. It just sums up and caps off the subject.



- 'Thank you very much for taking the time and for supporting us
- As already mentioned, we will provide you with further information and also a short summary of what we have discussed earlier
- Would you mind if I call your office in a few weeks to give you an update on our activities?'



# An instrument for your advocacy: The Call to Action for Newborn Health in Europe

## How was the Call to Action for Newborn Health in Europe developed?

A brainstorming workshop according to the so called World Café method at EFCNI's Parent Organisations Meeting 2018 formed the basis for the Call to Action for Newborn Health in Europe – in the following 'the Call to Action'. The outcome of these conversations were summarised in a first draft and in a second step, feedback by the Chair Committee of the European Standards of Care for Newborn Health project, was incorporated to develop the 14 key demands of the Call to Action. To have the backing of as many organisations as possible to advocate for these demands, the Call to Action was sent out to healthcare professional societies and parent organisations together with the final standards to ask for their support. Meanwhile, 120 healthcare professional societies and 51 parent organisations support the standards and endorse the Call to Action (status: September 2019).

## What is the Call to Action about?

The Call to Action is directed at various stakeholders: European and national policy makers, hospital administrators, insurers, professional and patient associations, as well as industry representatives. It calls upon them to work together to pave the way for the implementation of the standards. The Call to Action consists of 11 plus 3 demands – one for each of the eleven topics of the European Standards of Care for Newborn Health plus three general demands. The 11 demands corresponding to one of the Topic Expert Groups can be seen as a summary of what this specific topic is about and express the most pressing needs in this area. The 3 general demands show which overall aspects need attention in order to improve newborn healthcare across Europe. The Call to Action thus is a central document to advocate for the European Standards of Care for Newborn Health.

## How to use the Call to Action?

The Call to Action is a tool to promote the standards and to mobilise people to support them on a national level. It can be used in different ways – for several ideas on how to apply the Call to Action, e.g. via social media, please see chapter [Materials: Call to Action for Newborn Health in Europe](#).

The Call to Action was translated into 20 languages (status: September 2019). Please check on the website [www.newborn-health-standards.org/downloads](http://www.newborn-health-standards.org/downloads), if it is provided in your language. If it is not yet available in your language and you want to support us in translating the Call to Action for Newborn Health, please get in contact with us via [standards@efcni.org](mailto:standards@efcni.org) (see chapter [Materials: How to use the EFCNI materials](#)).



### NOTE

The Call to Action for Newborn Health in Europe can be accessed via [www.newborn-health-standards.org/call-to-action](http://www.newborn-health-standards.org/call-to-action).



## NOTE

Also global organisations like the UN, WHO and other NGOs issue Calls to Action, develop charters or conventions for a maximum outreach, it might be helpful to combine these action documents with the Call to Action for Newborn Health in Europe!

Have a look at the demands formulated e.g. in the:

- UN Convention on the Rights of the Child: [www.bit.ly/UN\\_Convention](http://www.bit.ly/UN_Convention)
- EACH Charter (European Association for Children in Hospital): [www.bit.ly/EACH\\_Charter](http://www.bit.ly/EACH_Charter)

## Set of arguments for the Call to Action and the standards

Whilst you are promoting the standards and pushing their implementation forward, you might be confronted with the question why standards of care in newborn health are so important and whether the current situation regarding the provision of care in your country or region is not already sufficient. Others might claim that only a small group of people/patients will benefit from the standards and improvements in neonatal care and that money and policy changes are much more needed in other fields of society.

As different stakeholders have different needs, we collated sets of arguments for 'parents and families', for 'healthcare professionals', and for 'health service, policy and research'.

Depending on whom you are talking to, you can choose from these sets of arguments and use them to convince your counterparts/negotiation partners to support the implementation of the standards in your country.

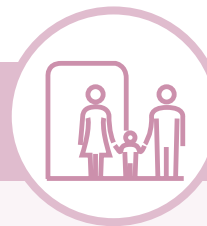


## NOTE

In order to develop your own set of arguments for specific standards, have a look at the statement of the standard together with the benefits section for inspiration. These two sections of the standard template are very useful to find arguments for each standard (please see chapter [Background information: The standard template](#)).

You find references for the standards at the end of every standard. These are very helpful to get more knowledge and to be a well-educated discussion partner! The standards can be accessed via [www.newborn-health-standards.org/standards/overview](http://www.newborn-health-standards.org/standards/overview).

### For parents and families



The involvement of parents in the care of their baby is extremely important for both the baby and the parents. This results in the following positive outcomes:

- ➔ Babies are discharged from the NICU earlier (1,2,3)
- ➔ Babies have improved long-term outcomes and a better cognitive development (4,5)
- ➔ Parents suffer less from stress and are supported in bonding with their child (2,6)

#### References:

- <sup>1</sup> Ortenstrand A et al. The Stockholm Neonatal Family Centred Care Study: effects on length of stay and infant morbidity. *Pediatrics*. 2010
- <sup>2</sup> Melnyk BM et al. Reducing premature infants' length of stay and improving parents' mental health outcomes with the Creating Opportunities for Parent Empowerment (COPE) neonatal intensive care unit program: a randomized, controlled trial. *Pediatrics*. 2006
- <sup>3</sup> Narayanan I et al. Maternal participation in the care of the high risk infant: follow-up evaluation. *Indian Pediatr*. 1991
- <sup>4</sup> Westrup B et al. Preschool outcome in children born very prematurely and cared for according to the Newborn Individualized Developmental Care and Assessment Program (NIDCAP). *Acta Paediatr Oslo Nor* 1992. 2004
- <sup>5</sup> Melnyk BM et al. Improving cognitive development of low-birth-weight premature infants with the COPE program: A pilot study of the benefit of early NICU intervention with mothers. *Res Nurs Health*. 2001
- <sup>6</sup> Mörelus E et al. A randomised trial of continuous skin-to-skin contact after preterm birth and the effects on salivary cortisol, parental stress, depression, and breastfeeding. *Early Hum Dev*. 2015

Early and continuous skin-to-skin care between mothers/fathers and their baby has a positive impact on the development of the child. This results in the following positive outcomes:

- ➔ Breastfeeding rates are increased (1)
- ➔ Parents are empowered to feel as a parent of their child, which has a positive impact on their mental health and reduces their stress (2,3)
- ➔ The sleep pattern of babies improves (4)

#### References:

- <sup>1</sup> Moore ER, Anderson GC, Bergman N, Dowswell T. Early skin-to-skin contact for mothers and their healthy newborn infants. *Cochrane Database Syst Rev*. 2012
- <sup>2</sup> Mörelus E et al. A randomised trial of continuous skin-to-skin contact after preterm birth and the effects on salivary cortisol, parental stress, depression, and breastfeeding. *Early Hum Dev*. 2015
- <sup>3</sup> Aghdas K et al. Effect of immediate and continuous mother-infant skin-to-skin contact on breastfeeding self-efficacy of primiparous women: a randomised control trial. *Women Birth J Aust Coll Midwives*. 2014
- <sup>4</sup> Peirano PD et al. Sleep in brain development. *Biol Res*. 2007



## For healthcare professionals



Hypoglycaemia in newborn babies is associated with risk for brain damage and neurodevelopmental sequelae, therefore measures need to be taken to prevent and manage this situation. This results in the following positive outcomes:

- Proper management of hypoglycaemia reduces the exposure of babies to this status (1)
- As hypoglycaemia has an impact on neurological outcome (2), a proper management improves the outcomes

### References:

<sup>1</sup> Deshpande S et al. The investigation and management of neonatal hypoglycaemia. *Semin Fetal Neonatal Med.* 2005

<sup>2</sup> Burns CM et al. Patterns of cerebral injury and neurodevelopmental outcomes after symptomatic neonatal hypoglycemia. *Pediatrics.* 2008

Retinopathy of prematurity (ROP) is the leading cause of childhood blindness which needs to be prevented, properly screened for and if necessary adequately treated. This results in the following positive outcomes:

- A proper prevention reduces the occurrence of severe retinopathy of prematurity needing treatment (1,2)
- Timely treatment can be provided (3)

### References:

<sup>1</sup> Chow LC et al. Can changes in clinical practice decrease the incidence of severe retinopathy of prematurity in very low birth weight infants? *Pediatrics.* 2003

<sup>2</sup> Zepeda-Romero LC et al. Oxygen Monitoring Reduces the Risk for Retinopathy of Prematurity in a Mexican Population. *Neonatology.* 2016

<sup>3</sup> AAP guideline. Screening Examination of Premature Infants for Retinopathy of Prematurity. *PEDIATRICS.* 2013

Preterm and ill babies often need to be resuscitated in the time course of their NICU stay. Therefore, regular neonatal resuscitation training for healthcare professionals is needed. This results in the following positive outcomes:

- Reduces the incidence of severe morbidities in the newborn period (1)
- Improves the long-term outcomes of the babies (2)

### References:

<sup>1</sup> Wyllie J et al. Guidelines for Resuscitation 2015 Section 7. Resuscitation and support of transition of babies at birth. *Resuscitation.* 2015

<sup>2</sup> Duran R et al. Effect of neonatal resuscitation courses on long-term neurodevelopmental outcomes of newborn infants with perinatal asphyxia. *Pediatr Int Off J Jpn Pediatr Soc.* 2012

### For health service, policy, and research



The access to data about neonatal and maternal care and the associated outcomes need to be ensured, while at the moment data collection it is not structured systematically neither on an international nor on a national level. This results in the following positive outcomes:

- Systematic data collection will improve the comparability of data and thus variabilities in care between countries can be better demonstrated (1,2)
- Measuring and benchmarking opens the opportunity to compare and thus detect areas of good practices and areas of poor practices (3)

#### References:

- <sup>1</sup> Infrastructure for Spatial Information in Europe. INSPIRE [Internet]. [cited 2018 Jul 10]. Available from: <http://inspire.ec.europa.eu>
- <sup>2</sup> Donabedian A. The quality of care. How can it be assessed? JAMA. 1988
- <sup>3</sup> Helenius K et al. Survival in Very Preterm Infants: An International Comparison of 10 National Neonatal Networks. Pediatrics. 2017

Perinatal care needs to be organised in specialist and non-specialist centres to ensure optimal care for mother and child. This results in the following positive outcomes:

- Women at risk for pregnancy complications get the optimal care they need which will result in improved maternal and neonatal outcomes (1,2,3,4)

#### References:

- <sup>1</sup> Neto MT. Perinatal care in Portugal: effects of 15 years of a regionalized system. Acta Paediatr Oslo Nor 1992. 2006
- <sup>2</sup> Marlow N et al. Perinatal outcomes for extremely preterm babies in relation to place of birth in England: the EPICure 2 study. Arch Dis Child Fetal Neonatal Ed. 2014
- <sup>3</sup> Bartels DB et al. Obstetrical volume and early neonatal mortality in preterm infants. Eur J Epidemiol. 2007
- <sup>4</sup> Wright JD et al. Regionalization of care for obstetric hemorrhage and its effect on maternal mortality. Obstet Gynecol. 2010

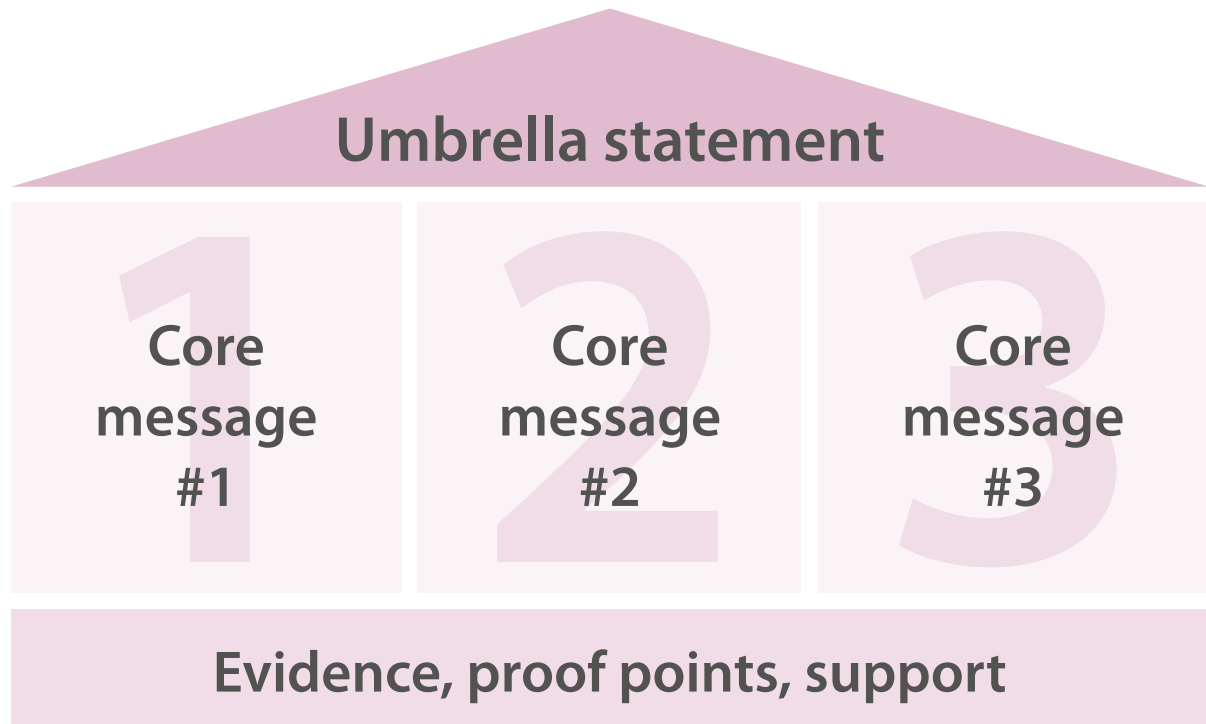
## Message house method

When talking about a certain project, it is often the case that different project members send different messages about it, or that joint messages are simply not heard, as the messages are not 'catchy' enough.

The message house method is a perfect tool that will help you to create strong messages to communicate and advocate for the standards in your country. If you compile different message houses for different stakeholders in one core set of messages, you can make sure that everyone involved in the communication about the standards understands and uses the same messages.

## How to build a message house<sup>3</sup>

In contrast to building a real house, you start with the roof when building a message house, and you then work down. There are different types of message houses. In the one we want to present to you, you have an 'umbrella statement' as the roof, which will be the key message that you want to convey to your audience. The house consists of three rooms below the roof, each containing one of the three supporting core messages. The whole house is kept together by the cellar, which is filled with 'evidence, support or proof'.



This method helps you to focus on the main messages you want to share and also to ensure that the whole team involved speaks with one voice. There are only three rooms in the house, so only the three main messages can make it into the message house.



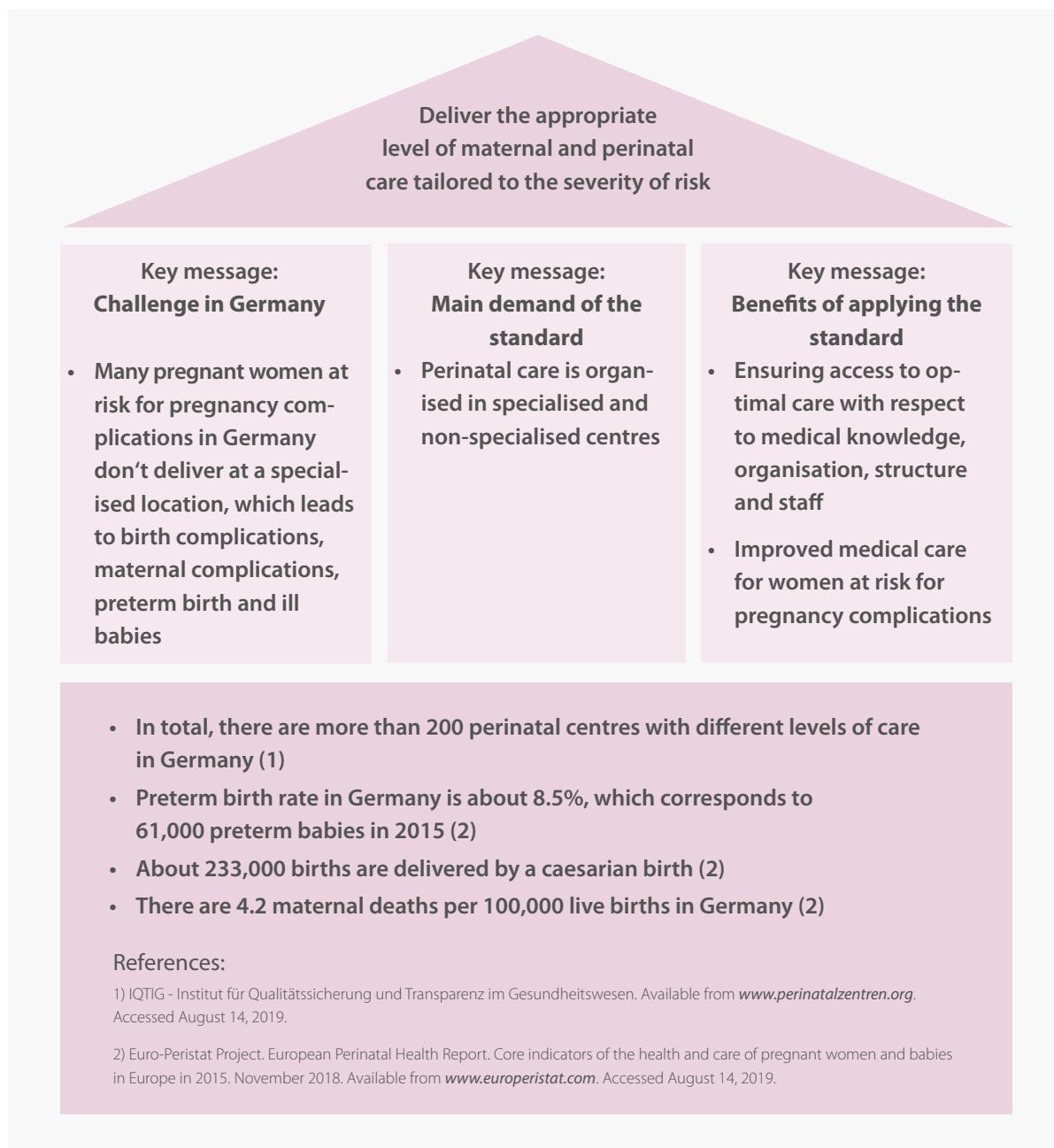
### NOTE

Before you start developing your message houses, create a thorough stakeholder map, and prioritise which standards you would like to start with (see chapter [How to get started: Stakeholder mapping](#)). Then generate very targeted message houses for the stakeholder(s) you would like to reach out about the respective prioritised standards.

Keep in mind that you need to find valid arguments for your cause and create the message house specifically for your own country!

<sup>3</sup> Developing a Message House. Available from: <https://De.slideshare.net/RichardHatheway/Developing-a-Message-House>. Accessed August 14, 2019.

The following is an example message house using the topic **organisation of perinatal care** in Germany. Please note that this is only an example containing a few points which need to be much more elaborated.



### NOTE

Develop several message houses for different stakeholders and compile them in a folder. You can e.g. laminate the single houses and provide your team with this folder in order to ensure that everyone speaks with one voice!

In order to prepare your own message houses, have a look at the 'rationale', the 'benefits', and the 'reference' sections of each standard.

## Summary: Advocacy in a nutshell<sup>4</sup>

Political context:		
What you need to know	What you need to do	How you can do it
<ul style="list-style-type: none"> <li>Who are the key decision/opinion makers?</li> <li>Is there any awareness for your topic?</li> <li>What is the policy making process?</li> <li>What are the sources/strengths of resistance?</li> <li>Who would be your ally/enemy?</li> <li>What are the opportunities and timing for input from your side?</li> </ul>	<ul style="list-style-type: none"> <li>Get to know the decision makers, their agendas, their constraints and keep regular contact</li> <li>Identify potential supporters and opponents</li> <li>Look out for unexpected policy windows and take action</li> <li>Observe ongoing policy actions and discussions and prepare for opportunities in regular policy processes</li> </ul>	<ul style="list-style-type: none"> <li>Observe the policy arena</li> <li>Build your networks Regularly exchange/talk with the key decision/opinion makers</li> <li>Attend high policy events</li> <li>Reserve resources to be able to move quickly in case of policy windows</li> </ul>

Evidence:		
What you need to know	What you need to do	How you can do it
<ul style="list-style-type: none"> <li>What is the current situation, gaps, lacks?</li> <li>What sort of evidence will convince policy makers?</li> <li>If you are affected: mention your personal story, this makes a strong impact</li> <li>Combine your experience with expertise, e.g. through common outreach together with healthcare professionals (20 % emotion, 80 % facts)</li> </ul>	<ul style="list-style-type: none"> <li>Keeping on with regular work and know your sources</li> <li>Establish credibility over the long term</li> <li>Name the problem and provide practical solutions</li> <li>Package new ideas in familiar words</li> <li>Communicate effectively</li> </ul>	<ul style="list-style-type: none"> <li>Look for allies and ideally set up pilot projects to demonstrate benefits of new approaches, or use pilot projects and their benefits from other countries as examples for success</li> <li>Use participatory approaches to help with legitimacy and implementation</li> <li>Have a clear strategy for communication from the start</li> <li>Search for face-to-face communication</li> </ul>

Links:		
What you need to know	What you need to do	How you can do it
<ul style="list-style-type: none"> <li>Who are the key stakeholders (positive/negative)?</li> <li>Which links and networks exist between them?</li> <li>Who are the intermediaries and do they have influence?</li> <li>Whose side are they on?</li> </ul>	<ul style="list-style-type: none"> <li>Identify potential supporters, key individuals and networks</li> <li>Get to know the key players, their priorities and constraints</li> <li>Identify persons who will be against your cause</li> <li>Establish credibility</li> <li>Keep an eye on the political arena and look out for policy windows</li> </ul>	<ul style="list-style-type: none"> <li>Develop extensive background knowledge on how policy processes work in your country</li> <li>Orient communications to your supporter's priorities and language</li> <li>Cooperate with others, seek allies</li> <li>Contact key individuals regularly</li> </ul>

<sup>4</sup>Tools for Policy Impact: A Handbook for Researchers. ODI. Available from:

<https://www.odi.org/sites/odi.org.uk/files/odi-assets/publications-opinion-194.pdf>. Accessed August 5, 2019.

## Do's and Don'ts in advocacy work

### DO'S



#### Collaborate with the personal assistants



A good relationship to the personal assistant, e.g. of a politician can help you to get an appointment much easier, as they are the ones who coordinate the meetings. So make sure to get a good relationship with them. Knowing their names is the first step!

#### Ask for an appointment



It makes sense to ask for an appointment a few weeks in advance, as politicians are usually very busy and have lots of appointments. Send an official email or a letter to request a meeting in which you describe who you and your organisation are and why you would like to meet (see [Appendix: Introduction letter template for a politician](#)).

#### Prepare yourself



Be sure you know where to go and also exchange contact details beforehand in case of any last minute changes.

Know the background of the person you talk to (there might be a preterm baby in his or her family or in the family of a colleague from the same political party!), know their vita and position to different related topics, and of course know what you want from them. Prepare your talking notes and practice (e.g. in front of the mirror) before the meeting.

It is also of utmost importance to know the facts by heart. You need to know as much as possible about the topic of relevance, know statistics of your country, know data from other countries so that you can show the comparison. Have a list in mind of things that you can offer the politician (e.g. a quote, a keynote lecture, a patronage of an event, etc.) and also how he or she could help you (always keeping in mind to ask for things where he or she is responsible for). Bring your business card with you!

#### Show your appreciation



At the beginning of the meeting, thank your counterpart for meeting with you despite their very tight schedule and express that you are very grateful for that.

#### Listen to your counterpart



Give the politician enough time to ask questions. Maybe they have a special interest in one certain issue. This might be the possibility to collaborate further!

## DO'S

**Make your point clear**

Know your key messages by heart and express them in a concise and short way. Be prepared that your meeting will only last for about 15-20 minutes, so start off with the most important points and don't babble.

If you have a personal story, consider sharing it briefly: personal stories make a powerful impact – but remember, that emotions should not exceed 20 % of the conversation and 80 % should be facts.

**See yourself as a source of information**

Be aware that the person you meet may not know everything about the topic. It is always easier for the politician to remember you and your cause if you leave something there. Therefore, prepare information material you could hand over. Ideally, provide your appointment with a one pager/ factsheet/briefing paper (ensure to point out correct and important information).

In case you do not know the answer to a question, do not try to make up facts/information. Politely tell your counterpart that you will find out the missing information and get back to him/her afterwards. In this case, make sure you follow-up quickly with the information requested.

**Express your expectations**

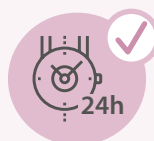
Know what you want to get from your counterpart. They might ask you the question: 'How can I help you?' This is your opportunity to ask for support or to give your recommendations.

**Be aware of politics**

Find opportunities where you can involve the politician in any upcoming media activities (World Prematurity Day could be such an option). Ask for a statement that you can publish together with your press release.

**Summarise the meeting**

At the end of the meeting, thank your counterpart for taking the time to meet with you. Do not forget to summarise the agreed action. Make sure to ask for a business card and hand over your own business card.

**Follow-up**

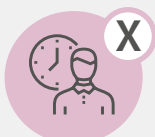
Ensure that you get back to the politician (or the personal assistant) within 24 hours! Thank them for the meeting opportunity and summarise what you were discussing and if there was anything you agreed on (e.g. next steps or a follow-up meeting). You can also add additional information to the topics the politician showed special interest in.



# DONT'S



## Don't ask for a meeting short notice



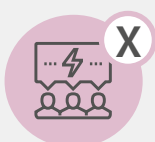
Politicians have an extremely tight schedule and therefore you cannot expect to get an appointment at short notice. Be aware and sensitive to their limited time, therefore don't call too often as this will definitely not increase your chances of getting an appointment.

## Don't go to the meeting unprepared



You will steal the time of your counterpart if you don't know what you want to say. In case your organisation is represented by a group who will meet with a politician, make sure everyone participating from your side got a briefing beforehand and knows what they want to express. Stick to the facts, use your own story only to explain the facts and always make sure that it is not only you that is affected by a certain fact, but a number of X families in your country, and show possible solutions! In a meeting of only 15 minutes, there is no time for talking too long about your personal story – 20 % emotion, 80 % facts.

## Don't claim: 'Politicians don't realise'



With such generalisations you might offend your counterpart. Better say sentences like: 'We believe that it is important to raise awareness about...'

## Don't make up facts or be inaccurate



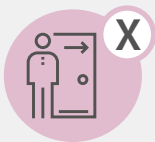
Of course you can get to a point where you don't know the answer to the question the politician asks you. This is not a big problem. Express that you are unsure at this point, but will do research and will provide the facts afterwards. But never make up facts or be inaccurate!

## Don't interrupt



Let your counterparts express their opinion and don't interrupt them. It is better to wait until he or she is finished before you clarify the issue or start the next one.

## Don't complain if the meeting is short



As already mentioned, politicians are extremely busy. Therefore, address the most important point first and be prepared to have only limited amount of time. Instead of complaining, thank for the time you get and send additional information afterwards.

## DONT'S

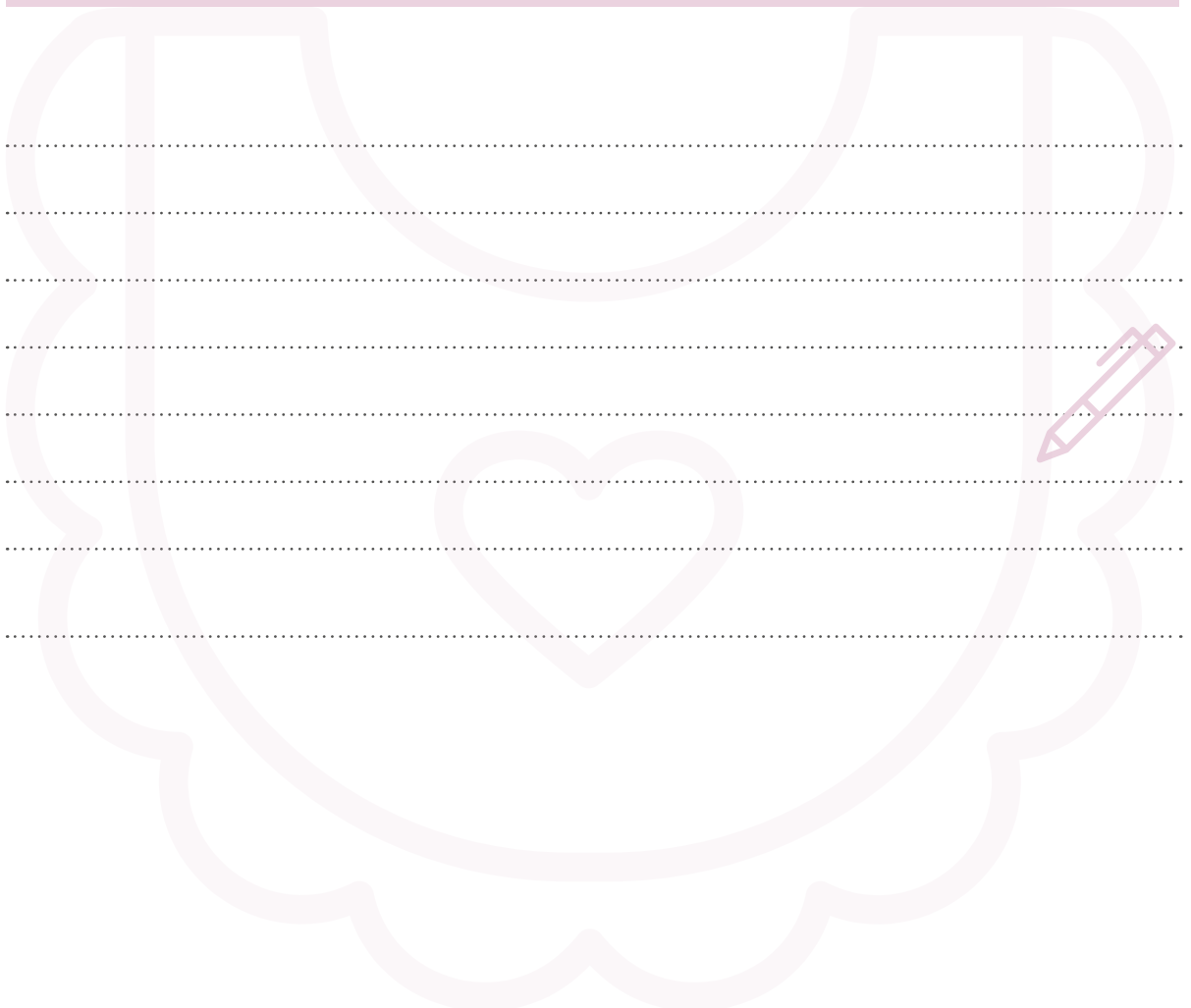
**Don't discard the relationship**

A relationship with a politician is always a long-term relationship. So don't abandon it if you have the feeling that you don't get any results. Ensure that you have a regular contact (about 2-3 times per year are optimal) where you give them an update on what you are doing and how they could support your cause.

**Don't surprise**

Think of briefing officials before you meet ministers, brief your relevant contact before you meet other politicians and opposition spokesmen and inform your contacts (if necessary with request for approval) before you publish any announcement relevant to them.

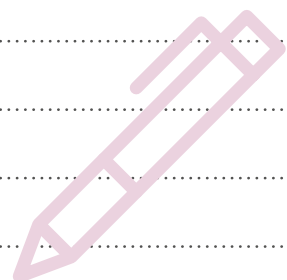
For questions or queries, please contact: [standards@efcni.org](mailto:standards@efcni.org).



## CHAPTER I Advocacy on EU and national level

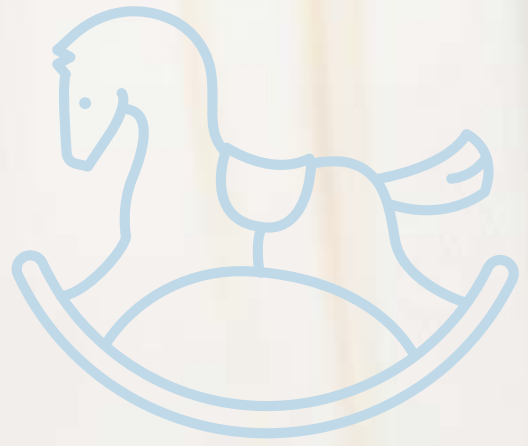


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CHAPTER

# Communication



# Communication

## Overview

- Communication strategy
- Communication plan
- Website
- Newsletter
- Social media
- Press and media
- Campaigning
- Promoting the standards on the occasion of World Prematurity Day
- Use awareness days for your promotion
- Live communication

Communication is key for the implementation of the European Standards of Care for Newborn Health – in the following ‘the standards’. The more people know about the newly developed standards, the more stakeholders will be interested in them, which will foster their implementation in Europe and in the future even beyond.

At the same time, engagement with multiple stakeholders on a local, national, and international level is a complex process (see chapter [How to get started: Stakeholder mapping](#)). Communication therefore must be clear, comprehensive, and coordinated.

In order to create a maximum outreach, we need to combine forces and speak with one voice. Join us in communicating about the standards and the Call to Action for Newborn Health in Europe by using all your available communication channels like your website, newsletter, social media channels, media contacts, or campaigns.

In the following, you find some practical advice and best practice methods for developing a communication strategy and to plan and manage your communication activities for both classic print media and online media platforms.

Consulting this toolkit, you will be able to:

- Create a successful communication strategy<sup>1</sup>, suitable to activate multiple stakeholder groups
- Structure your communication activities to inform and engage stakeholders to become active and compelling advocates for the implementation of the standards and the Call to Action for Newborn Health in Europe

<sup>1</sup>Planning Tools: How to write a communications strategy. ODI. Available from: [www.odi.org/publications/5186-planning-tools-how-write-communications-strategy](http://www.odi.org/publications/5186-planning-tools-how-write-communications-strategy). Accessed May 6, 2019.

## Communication strategy

Developing a targeted communication strategy is a critical step to support the implementation of the standards. Start from the stakeholder mapping and identification process (see chapter [How to get started: Stakeholder mapping](#)) to develop your outreach strategy to communicate about the standards.

For the communication strategy, make sure to consider the following aspects:

- Name your **objectives**
- Identify your **audience**
- Formulate clear **messages**
- Choose useful **tools and activities**
- Estimate your needed and available **resources**
- Set realistic **timescales**
- For the future: Carry out **evaluation** and be open to **amendments**



We recommend using a multi-channel approach within the communication strategy in order to reach a large/multi-stakeholder target group and to link all forms of communication and messages about the standards together. This approach could include website content, news about regular updates on the project, interviews, background features, videos, factsheets, and promotional materials both online and in print media, talks at scientific conferences and congresses, as well as political events.

### Objectives



What do you want to achieve with your communication?

Possible objectives could be:

- To promote and foster the implementation of the standards
- To raise awareness and inform about the standards
- To highlight the importance of newborn health in your country

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## Target groups/audiences



**Who do you want to reach and what might these stakeholders be interested in?**



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Know your audience: As part of the stakeholder mapping (see chapter [How to get started: Stakeholder mapping](#)), you should identify those audiences and key stakeholders who you want to reach and with whom you need to communicate to achieve your objective(s).

### Example

When organising a press conference to communicate about the standards, make sure to invite the local media and regional representatives of national media. Also think of inviting key stakeholders in this topic like healthcare professionals, politicians, parent and patient representatives.

## Messages



**What are your key messages?**

Knowing your audience and your objectives are key to your organisation's messages. To maximise the impact, you should summarise your communication about the standards in key messages which can be constantly repeated. Create a comprehensive example covering all key messages, and emphasise the different elements of the example for different audiences. You will find examples of key messages you can use for your communication in this chapter: [Social media](#). In addition, the 'Message house' helps you to develop localised and tailored messages for different stakeholders (see chapter [Advocacy on EU and national level: Message house method](#)).





## NOTE

In general, to promote the standards, choose messages which move the discussion from promoting a narrow topic (e.g. about a specific health complication in preterm and ill babies) to a broader, more comprehensive dialogue about prematurity and its consequences as a whole.

Remember that communication is all about storytelling: use narrative, human interest stories and arresting imagery, but make sure not to communicate overly emotional and to provide a supporting evidence base (e.g. headline facts and statistics – you can find further information which you might want to include in chapter [Background information](#)).

*When you tell your personal story to stress the need for the implementation of the standards in your country, you will be most credible for your audience if your narration is based on 20 percent emotions and 80 percent facts.*

*Silke Mader, Chairwoman of the Executive Board of EFCNI*



Reporting about your own experiences will be especially helpful when you speak to policymakers and the media as they will enable you to 'bring the story to life', highlight variations in the care of preterm and ill babies, but also point to good examples of care that exist in your country.

A good experience report will:

- Tell a compelling story
- Be easy to explain
- Be easy to understand
- Bring the issue to life by, for example, using quotes from parents and health-care professionals
- Enable people to relate to the issue
- Set out what the problem is and what action should be taken to address it

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## NOTE

**KISS - keep it short and simple - is the way to go.**

Example: World Prematurity Day by EFCNI: '1 baby in 10 is born premature. Worldwide! This is a simple message that transports what the campaign is about.



### Tools and activities



**Which tools and activities are most appropriate to communicate the key messages to the audiences?**

Please note that the tools and activities for your communication strategy depend on your audiences, messages, or a combination of the two. For example, an annual report is a useful tool when you want to be transparent about facts and figures with a sponsor whereas a newsletter provides information and updates more regularly, in smaller doses, and in a more narrative way suitable to update your organisation's members.

Especially for smaller organisations: ensure that you tailor your tools and activities to the level of time as well as human and financial resources available. Please find more information in chapter [Materials](#).

### Resources and timescales



**What resources do you have and what is the timeline for your communication strategy?**

Every small step makes a difference. The key rules to observe are always to deliver what you promise and never overpromise. Use your resources and timescales to set realistic goals and outline the case for more dedicated resources. There are many different types of resources, for example:

- **Financial resources** like donations, sponsorships, revenues from fundraising activities or charity events
- **Structural resources** like support in logistics, benefits in kind, provision of an event location, or pro bono agency services
- **Human resources** like volunteers, free expert advice, or employees of your organisation

A blue line-art icon of a pencil, indicating a writing or editing area.

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## Evaluation and amendment



Was your communication strategy effective?

Consider performing a communication audit to assess the effectiveness of your strategy with your audiences. To define your target groups and audiences, please see chapter [How to get started: Stakeholder mapping](#).

Discuss the results carefully and use them to amend your strategy. In case of scarce resources, think about simple ways of measuring impact, like social media statistics, tracking your website traffic, or asking key stakeholders for feedback via social media or email.



### Communication plan

In order to structure your communication activities, develop a communication plan that outlines dates and activities. This plan should contain details like the timeline, dates, planned content or topics, target groups, and channels (e.g. website, newsletter, social media). A communication plan can cover a shorter time span, for example, when it serves to structure and plan a timely limited campaign.

However, it can also be applied for long-term planning, covering the current year or even the upcoming year(s). Please find a template (see [Appendix: Communication plan](#)) for tips on how to set up your own communication plan that can be adapted according to the requirements and capacities of your organisation.

### Website

You can use your own website to highlight your engagement in developing, supporting, and implementing the standards. Much of the information that is distributed within your network could also be published on your site for quick reference along with other useful resources such as videos, latest news, links for media, images, and photos.

Here are some practical examples on how to promote the standards on your website:

- If you are supporting the standards with your logo, display on your organisation's website that you are a supporting partner of the European Standards of Care for Newborn Health project and that you are supporting the newly developed standards. Please also link to the official website of the project:  
**[www.newborn-health-standards.org](http://www.newborn-health-standards.org)**
- Explain the need for the newly developed standards and why they need to be implemented in your country. Another option would also be to display the Call to Action for Newborn Health in Europe. The Call to Action for Newborn Health in Europe is available in 20 languages – use your own language version on your website:  
**[www.newborn-health-standards.org/downloads](http://www.newborn-health-standards.org/downloads)**
- Share a news article and pictures of your latest events related to the standards (e.g. in a national hospital, a conference talk, a political event) on your website and promote it via your newsletter and social media (see next paragraphs)

You are always welcome to send information (text and photos) about your events to EFCNI at **[standards@efcni.org](mailto:standards@efcni.org)** and we will promote it in our newsletter or on our websites:

**[www.newborn-health-standards.org](http://www.newborn-health-standards.org)** and **[www.efcni.org](http://www.efcni.org)**.



#### NOTE

To prepare your website content, you are warmly invited to translate the informative texts on the official project's website into your national languages and to use our promotion material – for free download on our website:  
**[www.newborn-health-standards.org/downloads](http://www.newborn-health-standards.org/downloads)**.

## Newsletter

Regular newsletters are an ideal form of communication to raise awareness for the standards. Distribute your newsletter after important meetings or on a monthly or bi-monthly basis to your subscribers. If you already run a newsletter, you can of course add a news section dedicated to the standards to your newsletter to keep your subscribers updated.

Possible topics for your newsletter articles could be:

- Inform about events by your organisation, your supporters, or a local hospital
- Communicate about specific concerns raised during an event
- Show best practice examples from your country
- Report about a workshop for healthcare professionals on a certain topic (e.g. infant- and family-centred developmental care)



### NOTE

If you have any news regarding the implementation of the standards in your country, you can send it to **[standards@efcni.org](mailto:standards@efcni.org)** and we can include it in the next EFCNI newsletter!

Besides creating your own news, you can also share existing content from the EFCNI channels (at **[www.efcni.org](http://www.efcni.org)**, EFCNI newsletter, social media), for example:

- Progress in the implementation of the standards
- Latest news related to certain standards topics (e.g. infant- and family-centred developmental care)



### NOTE

When setting up a newsletter and registration form, always make sure to observe the legal requirements in line with the General Data Protection Regulation (GDPR) and general obligatory email marketing regulations!

### Social media

Besides your organisation's website or newsletter, use social media channels like Facebook, Twitter, Instagram, LinkedIn or YouTube, to raise awareness for the standards and the Call to Action for Newborn Health in Europe.



### How to share news on social media

Before you post, take some time to reflect which date or time of the day is most suited to posting. An awareness day can support the message you want to convey. It is also important to keep times of the day in mind when social media is highly frequented by users. For example, on workdays, the time people commute to work or take a lunch break are good windows of opportunity. Weekends are a less suitable time for posts as people engage more in social activities. However, if you post on weekends, choose a time before noon.<sup>2</sup>

### Sharing EFCNI's materials

Here are some examples of social media posts to share on your social media channels. The social media graphics below are only available in English, but you are more than welcome to translate the describing text (which is shared together with the picture) into your national language.

#### Step 1

Go to the social media graphics posted on the EFCNI channels (see examples on the following pages) or download social media graphics from the website:

***[www.newborn-health-standards.org/downloads](http://www.newborn-health-standards.org/downloads)***

#### Step 2

**Share** these graphics **with your network**:

- **Contact your private network** first **to reach a critical mass** – if your family members and friends share your messages, they can go viral and create a snowball effect
- **Create social media 'Business Profile' accounts** (available on Facebook and Instagram, free of charge) for your organisation and share messages via this profile
- Use your **personal profile and closed groups** only **in case of private, sensitive messages**, but not for social media posts targeted to a broader audience
- **Speak 'in the name' of your organisation** rather than just from your personal perspective



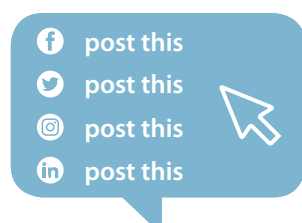
#### NOTE

Set up an official social media account (e.g. Facebook or Instagram 'business account') for your organisation – this will increase your visibility, credibility, and your professional appearance when promoting the standards.

<sup>2</sup>Best times to post on social media for 2019. Sproutsocial. Available from: [www.sproutsocial.com/insights/best-times-to-post-on-social-media](http://www.sproutsocial.com/insights/best-times-to-post-on-social-media). Accessed May 6, 2019.

Here are some sample posts you can use to go public about the standards and the Call to Action for Newborn Health in Europe on your social media accounts.

In the online version of the toolkit, you can also share the following graphics directly from EFCNI's social media channels by clicking on the respective icons called 'Post this'.



use this text



### Support parents in their role as primary caregivers

#NewbornHealthReloaded #Act4Babies

Copyright: EFCNI/Christian Klant Photography

[www.newborn-health-standards.org](http://www.newborn-health-standards.org)



use this text



### An investment in babies is an investment in our future

#Act4Babies #BetterStandardsBetterOutcomes

Copyright: EFCNI/Christian Klant Photography

[www.newborn-health-standards.org](http://www.newborn-health-standards.org)



f post this

t post this

@ post this

in post this



use this text



**Avoid the separation of mother and baby**

#BetterStandardsBetterOutcomes #EFCNIwecare

Copyright: EFCNI

[www.newborn-health-standards.org](http://www.newborn-health-standards.org)

use this text



**Working together – give parents and staff the chance to provide the best possible care for newborns**

#NewbornHealthReloaded #Act4Babies

Copyright: EFCNI

[www.newborn-health-standards.org](http://www.newborn-health-standards.org)

f post this

t post this

@ post this

in post this







### Commit to evidence-based healthcare

#BetterStandardsBetterOutcomes #EFCNIwecare

Copyright: EFCNI

[www.newborn-health-standards.org](http://www.newborn-health-standards.org)



### Support the Call to Action for Newborn Health in Europe

#Call2Action #Act4Babies

Copyright: EFCNI

[www.newborn-health-standards.org/call-to-action](http://www.newborn-health-standards.org/call-to-action)



use this text



### Support the European Standards of Care for Newborn Health

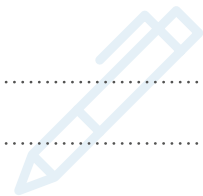
#11Months11Topics

#Act4Babies

Copyright: EFCNI

[www.newborn-health-standards.org](http://www.newborn-health-standards.org)

post this  
post this  
post this  
post this



## Creating your own social media posts

Alternatively, you can prepare your own social media posts (see following page: Summary of steps to consider when preparing a social media post):

- Choose a topic related image from your own photo stock or one of the social media graphics available at [www.newborn-health-standards.org/downloads](http://www.newborn-health-standards.org/downloads)
- Combine it with one of the messages (see this chapter: [A range of key messages for social media](#))
- Choose from the hashtags below
- Add a link to the website [www.newborn-health-standards.org](http://www.newborn-health-standards.org)
- Tag EFCNI's social media channels (see next page)

Combine your messages with one or some of these hashtags:

**#BetterStandardsBetterOutcomes**

**#EFCNIwecare**

**#Act4Babies**

**#NewbornHealthReloaded**

**#Call2Action**



### NOTE

To be included in the global outreach tracking, make sure to tag EFCNI's social media accounts in all your social media posts.



/efcni



@EFCNIwecare



@efcni



/company/efcni---european-foundation-for-the-care-of-newborn-infants/



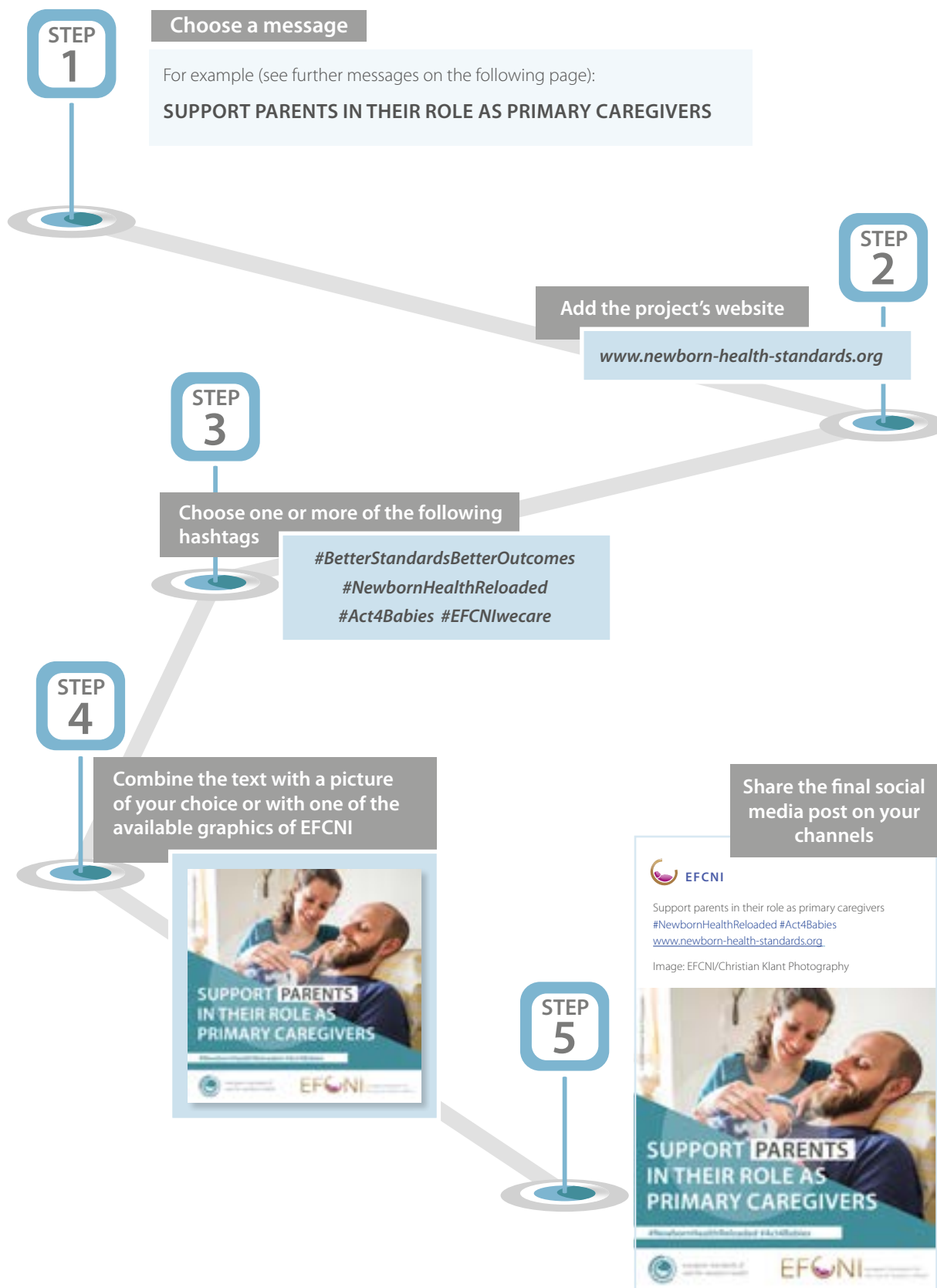
/user/EFCNIwecare



efcni.org

## Summary of steps to consider when preparing a social media post

What should a social media post on the European Standards of Care for Newborn Health look like?



*A range of key messages for social media*

You can choose from the following messages and translate them into your language. You can use these messages for any kind of social media account (Facebook, Instagram, Twitter, etc.). But of course, you are also warmly welcome to create your own messages based on the standards.

- Identify women at risk for preterm birth early
- Avoid the separation of mother and baby
- Commit to evidence-based healthcare
- Support parents in their role as primary caregivers
- Invest in sufficient specialist staff, particularly nurses and midwives
- Support optimal nutritional care that meets the baby's individual needs
- Promote shared decision-making between healthcare professionals and parents
- Ensure patient safety and adherence to hygiene practices
- Collect data, measure, compare, act
- Define indicators for long-term health and developmental outcomes
- Provide continuous education and training for all healthcare professionals working in maternal and newborn healthcare
- Establish national frameworks for strategies to minimise risks before, during, and after birth
- Support research into maternal and newborn health
- An investment in babies is an investment in our future
- Working together – give parents and staff the chance to provide the best possible care for newborns

**NOTE**

Besides communicating on your own social media accounts, please also support the standards in sharing EFCNI's social media posts on Facebook, Twitter, Instagram, and LinkedIn with your network, either as it is, or with an additional translation below.

**What else to keep in mind?***Tracking*

To evaluate the success of your social media posts, make use of tracking tools like Google Analytics, Facebook Insights, Instagram Insights, etc. Please note that the tracking options for Facebook and Instagram are only available if you create a 'Business Profile' (instead of a personal profile).

Also make sure to use some of the above mentioned hashtags. Via these hashtags it is possible to track all activities around the communication about the standards and show the outreach.

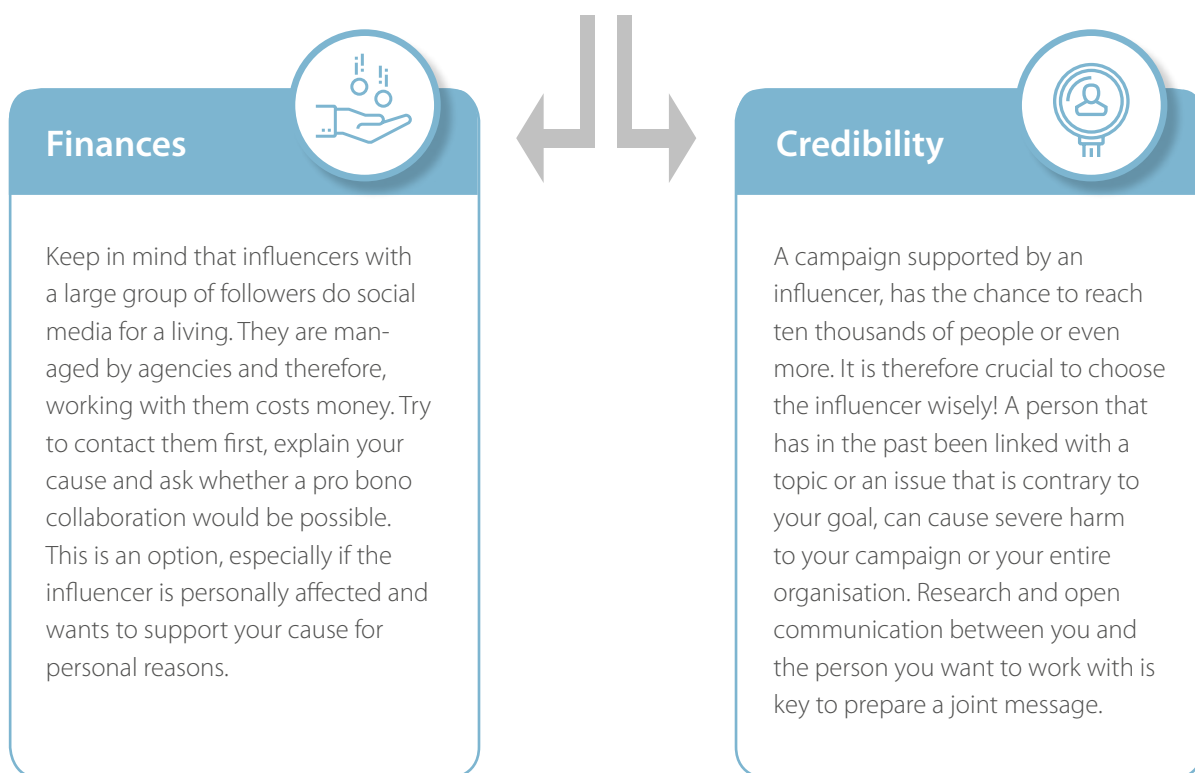
**NOTE**

Build and take advantage of a widespread network of followers on social media including key organisations in maternal and newborn health. A repost by one of your influential followers can effect a tenfold increase in your social media outreach and create a snowball effect. Be equally active and like and repost content that supports your cause issued by others in your network.

**Example****Creating a snowball effect - the power of the network**

*Working with influencers*

To reach both a wide public and a targeted audience, it can be helpful to collaborate with influencers, i.e. people who have developed a solid range on social media with the ability to affect decisions and opinions. Working with an influencer can make a campaign go viral as their network will spread a message or a picture within seconds. This makes so called influencer marketing attractive. However, **there are a few things you should keep in mind if you consider to collaborate with an influencer:**

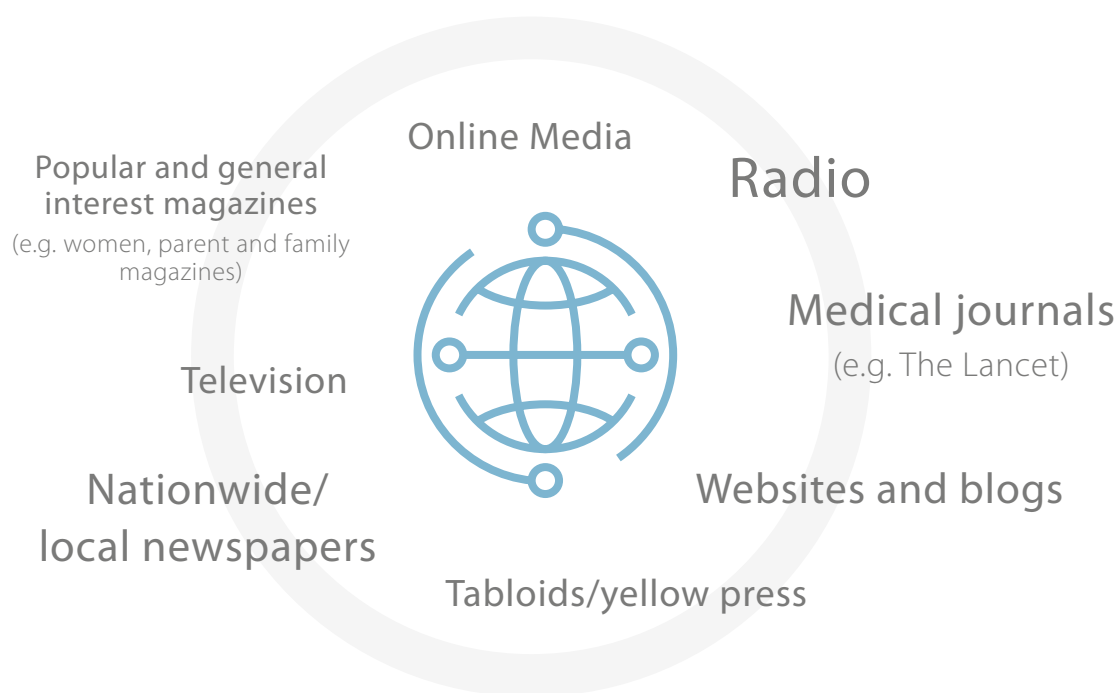
**NOTE**

Identify an influencer who has been active within the field of newborn or maternal health, healthcare, politics or charity as such; try to contact them via direct messages on their social media profiles and prepare your request for a collaboration well.

## Press and media

Proactive engagement with the media is a crucial aspect to communicate about the standards and the Call to Action for Newborn Health in Europe. Involve your national press and media to make them aware of these topics. As multipliers, they have the ability to spread our messages among a vast target group.

There are various types of media you can contact, for example:



### *Timing*

Remember that timing is key – profit from the ‘golden opportunity’ for your press and media activities: send out your press release every time there is a special occasion and a development within the implementation of the standards, e.g. a workshop in your local hospital, a political event, a special awareness day (see this chapter: [Use awareness days for your promotion](#)) etc. or create an occasion, e.g. by setting up a new campaign or a press conference.



*Ways to address the media*

- Press release
- Personal email
- Telephone

One way to address the media, is to develop a press release. Press releases can be published on your website, distributed to your media contacts and sent to your partners.

**NOTE**

Please use our template (see [Appendix: Media release template](#)) to develop a press release for your upcoming event related to promoting the standards.

Please keep in mind that the style of press releases varies from country to country. Please see attached (see [Appendix: Media release template](#)) for tips on how to write an effective press release that can be adapted according to the requirements in your country.

Furthermore, feel free to use this document as a basis for your own press release. A possible structure of your press release could be the following:

First paragraph	The 'name of your organisation' is supporting the European Standards of Care for Newborn Health and the Call to Action for Newborn Health in Europe.
Second paragraph	Point out the situation of preterm and ill babies and their families in your country, based on a supporting evidence base (see chapter <a href="#">Background information: Data and supporting evidence base</a> ).
Third paragraph	Include a quote from a key opinion leader or president of an important national healthcare society or parent organisation.

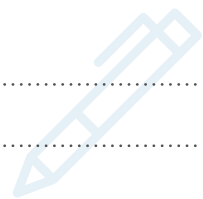
**NOTE**

If your press release is published in the media, please inform us via **[standards@efcni.org](mailto:standards@efcni.org)** so we can track and share this, to maximise the outreach.

For further advice on how to involve press and media in every phase in the organisation of your event, please see this chapter: [Live communication](#).



© Shutterstock



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## Campaigning

### How can you campaign for the standards and the Call to Action?

Communicate about the European Standards of Care for Newborn Health and about the Call to Action for Newborn Health in Europe by joining an existing campaign (e.g. EFCNI's 11 Months – 11 Topics campaign, see below) or by starting your own campaign.

### Steps to successful campaigning

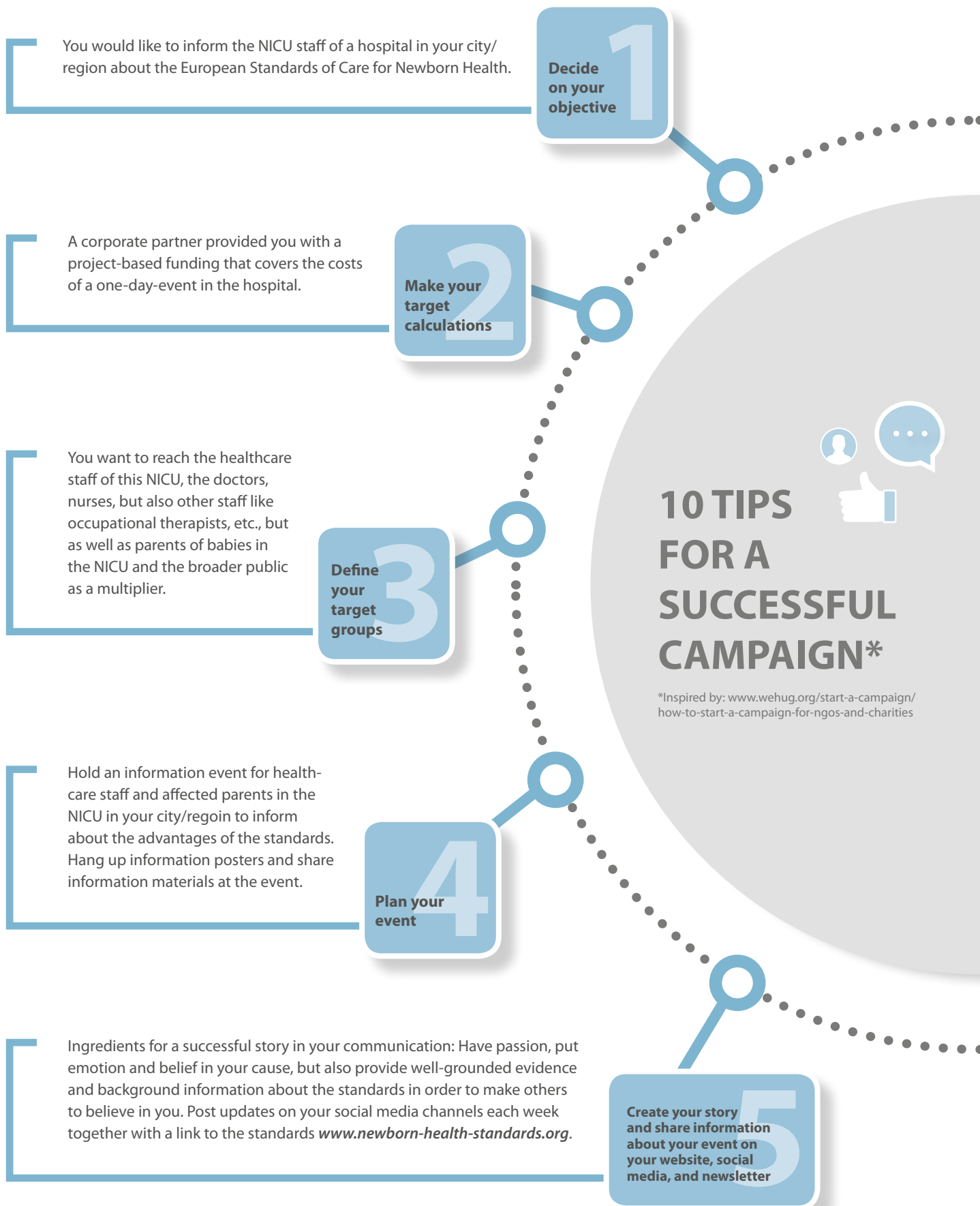
In general, the following steps can inspire you to run a campaign of your own<sup>3</sup>:

- Identify your issue
- Set your goals
- Create a resource pool
- Plan for success
- Develop campaign tactics and get your message across



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<sup>3</sup> Steps to Campaigning Success – Student Handbook. Museums Libraries Archives Council. Available from: [www.bl.uk/learning/resources/pdf/makeanimpact/mairesource.pdf](http://www.bl.uk/learning/resources/pdf/makeanimpact/mairesource.pdf). Accessed May 6, 2019.



## 10 Evaluate your event and the campaign

Come together with your team and the stakeholders involved for a wrap-up of your event and communication, analysing what went well and what can be optimised. Share a short survey via your online channels, asking others for feedback on the campaign.

## 9 Post updates on your website and social media

Inform your stakeholders and the corporate partner what you have achieved with their money and (pro bono) support, show videos, and pictures. Prove your trustworthiness! You may need their help again.

## 8 When the campaign is over, celebrate if you reached your goal

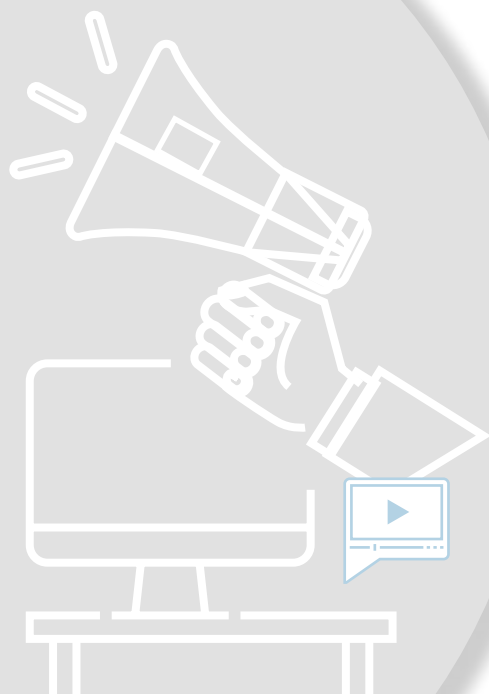
Thank all the people who helped you! Celebrate the successful event with your team and follow-up with healthcare professionals and parents who joined your event.

## 7 Hold the event and provide information about the standards

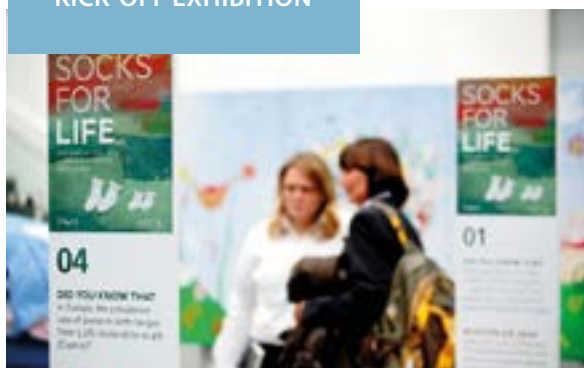
Hold the event and make sure to send out your invitation early enough in advance. At the event, contribute to the programme by providing the parent perspective about the topics. At the hospital, share information brochures and information flyers, both for healthcare professionals and parents. Make the standards visible, e.g. refer to the website [www.newborn-health-standards.org](http://www.newborn-health-standards.org).

## 6 Recruit others to help you

Enrol others to support your event early in advance: Ask an expert who had been involved in the development of the standards to join your event and to provide first-hand information about the standards. Make sure to involve the heads of the hospital unit in the programme of your event and ask the public relations department to raise awareness for your cause. Ask followers to share content about your cause, promote it as much as you can. Invite media to your event and ask them to report about it. EFCNI can also support you in promoting your event.

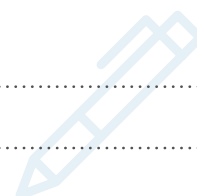


KICK-OFF EXHIBITION



The kick-off event for the European Standards of Care for Newborn Health project, the Socks for Life exhibition was presented in the European Parliament in April 2014.

© EFCNI





## Campaign 11 Months – 11 Topics by EFCNI

### *What is the campaign about?*

Initiated in 2016, 11 Months – 11 Topics is an ongoing and year-round campaign by EFCNI to promote the European Standards of Care for Newborn Health and to support their implementation.

### *What are the aims of the campaign?*

- Raise awareness about the eleven core topics covered in the project
- Support the implementation of the standards and of the Call to Action for Newborn Health in Europe

### *What are the target groups?*

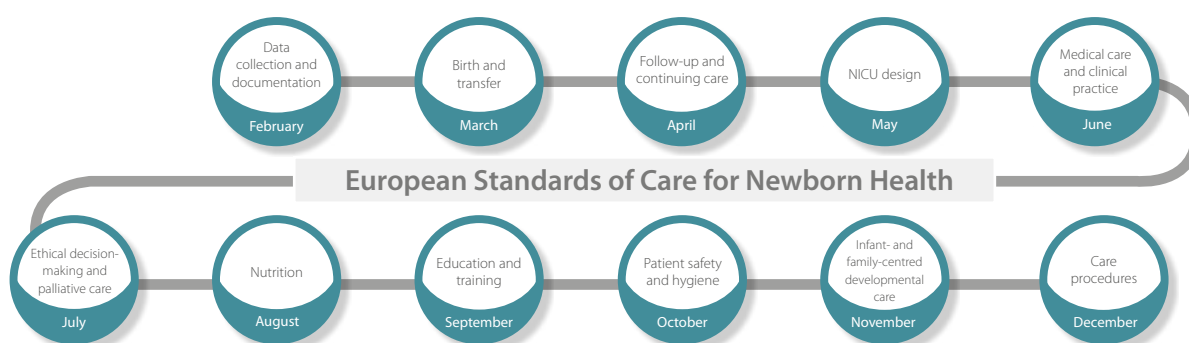
- Healthcare professionals
- Key opinion leaders (KOLs) like policy makers, Non-Governmental Organisations (NGOs)
- Multiplicators like parent representatives
- Industry representatives
- Hospital administrators

For regular updates about the campaign, please go to:  
**[www.efcni.org/11-months-11-topics](http://www.efcni.org/11-months-11-topics)**.

### *How is this put into practice?*

In the eleven months from February until December, EFCNI's online and social media communication focuses each month on one of the eleven core topics of the European Standards of Care for Newborn Health.

Here is an overview of when these topics are featured:



Each month, EFCNI shares **content related to one of these eleven core topics**, e.g.:

- Repetitive components like general information about the topic, statements, etc.
- Up-to-date information like news, interviews, or guest articles by EFCNI's collaboration partners and experts involved in the development of the standards
- Best practice examples (so called 'lighthouse projects') that show how the standards can be put into practice
- Research news about latest publications
- Further information about selected standards
- Infographics and materials for download

## Example

The following examples show how the topic of NICU design has been featured in the month of May over the last years since the launch of the 11 Months – 11 Topics campaign in 2016.

Every year of the ongoing campaign 11 Months – 11 Topics, there have been different repetitive components, which were supplemented by up-to-date information, e.g. research articles. Exemplary, it is shown how the content in the month of May, featuring NICU design, has changed its look and feel over the years.

2016

### Parent statement



### Interview with Chair team



### Campaign statements on NICU design



2017

### Parent statement



### Thank You card



2018

### Announcement of the topic month



### Introduction of lighthouse projects



### Standard titles compiled in a mindmap



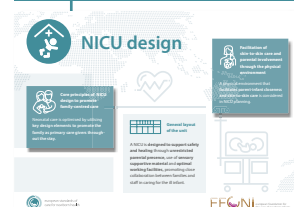
TO BE CONTINUED...

2019

### Social media graphic of a selected standard 'in brief'



### Overview of statements of standards



### Infographic of a selected standard 'in brief'



### Call to Action statement





*How can you join the campaign?*

The following options are available:

1. Support EFCNI's campaign activities. Select one or more of the monthly topics (see above) and

- Like and share EFCNI's social media posts and news on your channels
- Share 'Thank you' cards with your network, healthcare professionals, etc.
- Share research news related to the monthly topic
- Share EFCNI's Call to Action for Newborn Health in Europe statement and photos (see chapter [Materials: Call to Action for Newborn Health in Europe](#))

2. Create your own content to support the campaign. Select one or more of the monthly topics and

- Find 'lighthouse projects' in your country
- Present information about the standards in general
- Find newsworthy projects in your country in the topic field
- Lead an interview with a key stakeholder in the field
- Start a campaign related to the monthly topic (e.g. a campaign during World Breastfeeding Week or an article about parenteral nutrition corresponding to the monthly theme 'Nutrition' in August)
- Show practical examples on how the standards are implemented in your country (e.g. a hospital that changes its visiting hours for parents to 24/7)
- Share statements by affected parents and healthcare professionals from your local hospital
- Share your Call to Action for Newborn Health in Europe together with your own statement and photo

In addition to joining an existing campaign like 11 Months – 11 Topics, you can also start your own campaign. In the following, you can find two inspiring examples by two of EFCNI's partner organisations.

## Campaign 'Born with the Sign of a Genius' by Neišnešiotukas, Lithuania

*What is the campaign about?*

In 2017, the Lithuanian parent organisation Neišnešiotukas started the photo exhibition and campaign 'Born with the Sign of a Genius'. The idea behind the campaign is to encourage parents to discover the strengths and 'genius' in their preterm born children instead of focusing on their illnesses.

*What are the aims of the campaign?*

- Help families of preterm born and ill children believe and trust in their child, motivate, and develop his/her talent and shape a positive attitude within society towards preterm born and ill children
- Learn more about the problems and the situation in local areas
- Encourage the community (families, doctors, politicians, corporate partners, etc.) to improve the care of preterm and ill babies in Lithuania by implementing the European Standards of Care for Newborn Health

### *What are the target groups?*

- Preterm and ill children and their families
- Parent and patient organisations
- General society
- Politicians and lobbyists
- Media
- Non-governmental organisations (NGOs)
- Healthcare professionals and other key stakeholders

### *How is this put into practice?*

An exhibition of photos by children born preterm, dressed up to resemble famous preterm born people like Albert Einstein, Mark Twain or Winston Churchill taken by a professional photographer, was at the heart of the campaign. For nine months, the photo exhibition toured through nine cities all over Lithuania.

In addition, several side events were held, like visiting local hospitals, meetings with the Lithuanian Ministries of Health, Social Security, and Education, a roundtable with academics, the Disability and Working Capacity Assessment Office, and the local municipality administrations. Another part of the campaign was a fundraising cooperation with 32 book stores of a nation-wide famous book chain in which the stores around the country donated a part of the revenues of their book sales to Neišnešiotukas.

### *What can you learn from this campaign?*

#### **Advice by Asta Speicyte Radzeviciene:**

- Find a creative idea for your campaign to link to the broader topic of the European Standards of Care for Newborn Health
- Provide supporting and easy-to-understand background information (e.g. national and global preterm birth rates, latest research, etc.)
- Distribute time and human resources efficiently, plan sufficient time to participate in events and networking
- Choose a competent team and identify the right contact persons
- Involve celebrities and politicians and be in touch with the politician's whole team
- Collaborate with community representatives
- Involve the media early in advance to receive a broad local and national media coverage

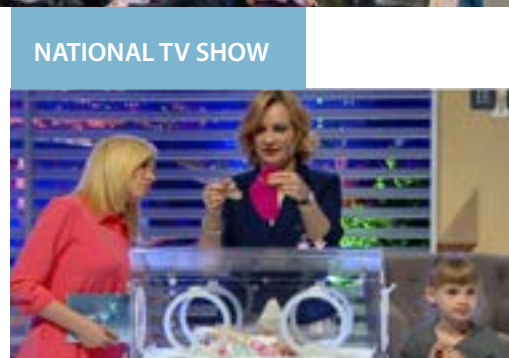


*Our campaign was an excellent way of getting in contact with local hospitals, politicians, and affected parents and turned out as a good instrument to introduce the standards in Lithuania.*

*Asta Speicyte Radzeviciene,  
CEO of Neišnešiotukas and  
Member of the EFCNI Parent  
Advisory Board*

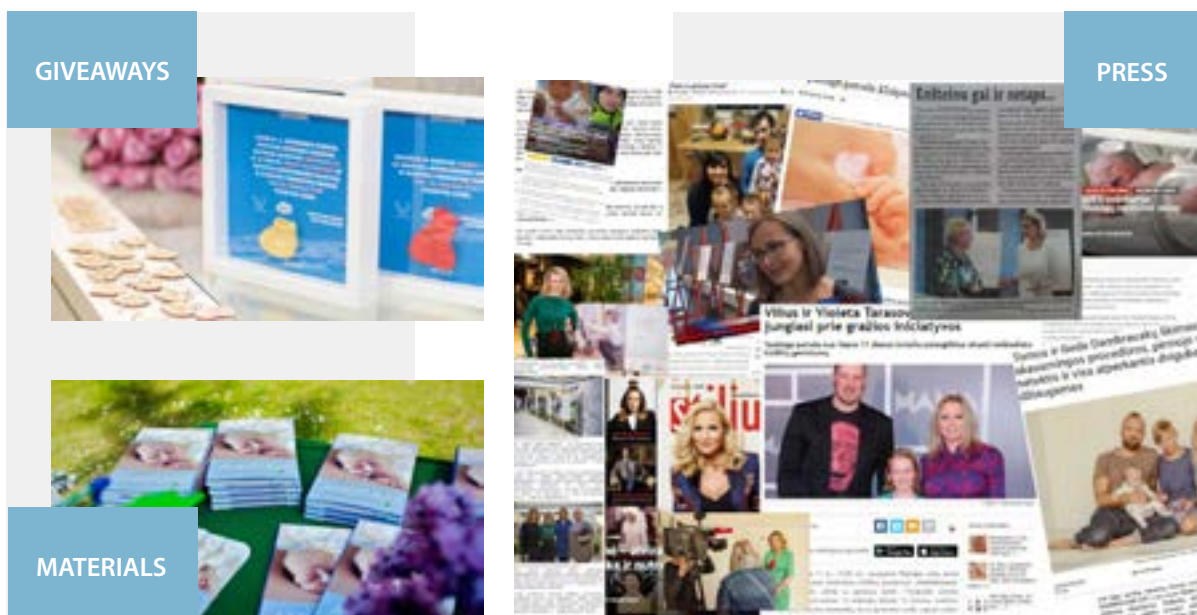
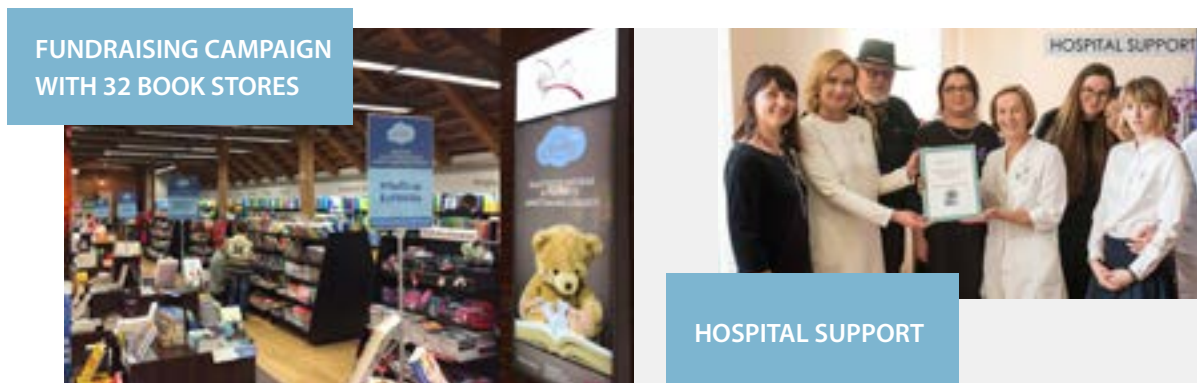


© Neišnešiotukas/Jurate Karkauskiene



© Neišnešiotukas





## Campaign 'Dads in the focus' by Ранні пташки (Early Birds), Ukraine

### *What is the campaign about?*

The parent organisation Ранні пташки (Early Birds) from the Ukraine launched a photo exhibition 'Dads in the focus' with the support of the Ministry of Health of the Ukraine, the Ukrainian Association of Neonatologists, as well as the main perinatal centres and maternity hospitals. The exhibition stressed the importance of fathers in the neonatal intensive care unit (NICU) as equal partners in parental care and care practices like skin-to-skin care.

### *What are the aims of the campaign?*

- Underline the need to involve fathers in the care of their child
- Increase knowledge about the standards and motivate healthcare professionals to implement care practices like infant- and family-centred developmental care, skin-to-skin care, and further issues that are demanded in the standards

### *What are the target groups?*

- Parents, especially fathers affected by preterm birth and parent organisations
- Other family members like grand parents
- General society
- Politicians and lobbyists
- Media
- Non-governmental organisations
- Healthcare professionals and other key stakeholders
- Employers and colleagues

### *How is this put into practice?*

The campaign consisted of a photo exhibition that was first presented in Kiev on World Prematurity Day 2018. The emotional pictures had been taken by different Ukrainian photographers – many of which themselves affected by preterm birth – showing fathers of preterm and ill babies taking care of their child, e.g. practicing skin-to-skin care in the NICU. Later, the exhibition was on display at several other occasions like the annual Parent Organisations Meeting by EFCNI in January 2019.

In addition, Ранні пташки (Early Birds), the Association of Neonatologists of Ukraine, the Institute of Pediatrics, Obstetrics and Gynecology of NAMS of the Ukraine, DP 'IPAG NAMS of Ukraine' and Shupyk National Medical Academy of Postgraduate Education, held an international conference on 'Modern approaches to rehabilitation of preterm babies and children at an early age: Ukrainian realities' in Kiev, Ukraine.



© Ранні пташки (Early Birds)



© Ранні пташки (Early Birds)

*We should encourage and appreciate fathers to take care of their baby in the NICU, as it is demanded in the European Standards of Care for Newborn Health. This does not only strengthen the bonding process between the father and the child but also benefits the whole family.*



*Oleksandra Balyasna, CEO of Ранні пташки (Early Birds) and  
Member of the EFCNI Parent Advisory Board*

*What can you learn from this campaign?*

**Advice by Oleksandra Balyasna:**

- Tackle a sensitive topic by connecting it to a broader and more comprehensive dialogue
- Create a deeper understanding and use the power of 'real stories' by involving persons affected by preterm birth in as many steps of the campaign as possible (e.g. photographers who themselves experienced the challenges of preterm birth)
- Involve key opinion leaders like politicians to become ambassadors for your cause





## Promoting the standards on the occasion of World Prematurity Day

### How can you use World Prematurity Day to promote the standards?

World Prematurity Day on 17 November is one of the most important days in the year to raise awareness of the challenges and burden of preterm birth globally. The day was initiated by EFCNI and partnering European parent organisations in 2008. The international co-founders LittleBigSouls (Africa), March of Dimes (USA) and National Premmie Foundation (Australia) joined the celebrations and made World Prematurity Day an intercontinental movement. Meanwhile, countless individuals and organisations from more than 100 countries join forces with activities, special events and commit to action to help address preterm birth and improve the situation of preterm and ill babies and their families.

World Prematurity Day is an excellent occasion to start your own campaign and to take this as an occasion to communicate about the standards and the Call to Action for Newborn Health in Europe. Every year, World Prematurity Day is celebrated under a global motto to combine forces and to maximise the awareness for preterm birth world-wide. The joint, global motto manages to create a link between World Prematurity Day and the promotion of the standards.

View more about the history of World Prematurity Day, materials (including a special World Prematurity Day toolkit, graphics in about 40 languages, etc.), and find regular updates on the global motto at: **[www.efcni.org/worldprematurityday](http://www.efcni.org/worldprematurityday)**.





### NOTE

If you plan an event (e.g. an expert roundtable, workshop for healthcare professionals, or a political event) around World Prematurity Day, make sure to allow for sufficient lead time and financial resources. For further recommendations, please see chapter [How to get started](#).

### Example

#### Examples of events you can organise around World Prematurity Day

- Plan an expert roundtable related to one of the topics of the European Standards of Care for Newborn Health (see chapter [How to get started: Organising an expert meeting](#))
- Organise a training workshop or a conference for healthcare professionals based on the standards
- Hold a political event in cooperation with your local politicians





## Use awareness days for your promotion

### How can you use other awareness days as a hook to promote the standards?

In addition to World Prematurity Day, you can use further awareness days related to newborn health to communicate about the standards throughout the year. Awareness days (and weeks, months, and years) are declared by various organisations, groups or governments to raise awareness of an issue, commemorate a group or event, or celebrate something.

Here are some examples for awareness dates you could use to promote the standards and the Call to Action for Newborn Health in Europe:

### Awareness dates (examples)

<b>February</b>  <b>Rare Disease Day</b> (Last day of February)	<b>July</b>  <b>World Bereaved Parents Awareness Month</b>	<b>October</b>  <b>World Sight Day</b> (10 October)  <b>Global Handwashing Day</b> (15 October)
<b>May</b>  <b>Parents of Premies Day</b> (1st Sunday in May)  <b>World Hand Hygiene Day</b> (5 May)  <b>International Day of the Midwife</b> (5 May)  <b>International Nurses Day</b> (12 May)  <b>Kangaroo Care Awareness Day</b> (15 May)  <b>World Human Milk Donation Day</b> (19 May)  <b>World Pre-eclampsia Day</b> (22 May)  <b>Pre-eclampsia Awareness Month</b>	<b>August</b>  <b>World Breastfeeding Week</b> (1st week of August)  <b>International Neonatal Nurses Day</b> (15 August)	<b>November</b>  <b>World Prematurity Day</b> (17 November)
	<b>September</b>  <b>World Lung Day</b> (25 September)	





### NOTE

There are even more awareness days related to newborn health you can use for your communication. For an overview, please go to: [www.efcni.org/awareness-days](http://www.efcni.org/awareness-days).

For your inspiration, here are some specific examples of how you can use these awareness days to promote the standards and the Call to Action:

- **Rare Disease Day** (last day of February): Many health conditions that can be a life-long challenge for pre-term and ill babies, are so called rare diseases, which means that it affects not more than 5 in 10.000 people (EMA definition). For example, the chronic respiratory disease Bronchopulmonary dysplasia (BPD) is a rare disease. Use the awareness day to share information on the prevention of BPD and promote the standard 'Prevention of Bronchopulmonary Dysplasia (BPD)'. Post a message on social media and change your social media covers using the official Rare Disease Day graphic<sup>4</sup> materials
- **Parents of Premies Day** (first Sunday in May): Highlight the importance of integrating and empowering parents to take care of their hospitalised child, e.g. by sharing a picture of parents in the NICU and link to the standards in the field of infant- and family-centred developmental care. Another option is to emphasise the need to involve parents in decision-making processes in hospital and to provide information materials for parents (e.g. by linking to the [factsheet](#) in EFCNI's download section at <https://www.efcni.org/activities/downloads>)
- **International Day of the Midwife** (5 May)/**International Nurses Day** (12 May)/**International Neonatal Nurses Day** (15 August): Midwives and nurses play a key role in the care of preterm and ill babies and thus in the implementation of the standards. Choose a suitable picture, share a thank you message to midwives/nurses in general or in your local hospital on social media and highlight their importance in putting the standards into practice and the fact that nurses (together with other healthcare professionals and stakeholders) have been contributing to the development of the standards
- **Kangaroo Care Awareness Day** (15 May): Many of the standards refer to the importance of skin-to-skin contact or so called kangaroo care (e.g. the standards 'Support for parental-infant bonding' or 'Very early and continuous skin-to-skin contact'). Share information about selected standards and publish an interview with a healthcare professional from your local hospital or an affected parent who shared her/his experiences and/or gives practical advice in kangaroo care/skin-to-skin care
- **World Human Milk Donation Day** (19 May): One of the aims of the standards is to foster the set-up of human milk banks (e.g. the standard 'The role of human milk banks'). Promote the workshops of the EFCNI Academy in this field and share EFCNI's position paper and toolkit for establishing and organising human milk banks available at [www.efcni.org/milkbanks](http://www.efcni.org/milkbanks)

<sup>4</sup>Rare Disease Day. Available from: [www.rarediseaseday.org](http://www.rarediseaseday.org). Accessed from May 6, 2019.

- **Pre-eclampsia Awareness Month** (May) and **World Pre-eclampsia Day** (22 May): Join EFCNI's annual social media campaign about pre-eclampsia, a life-threatening pregnancy complication, by sharing EFCNI's videos, graphics, and social media posts. Add a link to further information on pre-eclampsia (e.g. to the EFCNI website or, if available in your language, to your own website) and refer to one of the related standards, e.g. on '[Information provision for women about the risk for preterm birth \(PTB\)](#)'
- **World Bereaved Parents Awareness Month** (July): Share EFCNI's social media posts related to the monthly topic of '[Ethical decision-making and palliative care](#)' within the campaign 11 Months – 11 Topics (see this chapter: [11 Months – 11 Topics](#)), share a link to the related standards, to the respective Call to Action for Newborn Health in Europe (see more at [www.newborn-health-standards.org/call-to-action](http://www.newborn-health-standards.org/call-to-action) and chapter [Advocacy on EU and national level](#)), to related content, or a project (e.g. [Guidelines on Palliative Care by the German Federal Association Bundesverband 'Das frühgeborene Kind' e.V.](#) or the [Neonatal Butterfly Project](#))
- **World Breastfeeding Week** (1st week of August): Create a campaign on the benefits of breastfeeding (poster, social media, collaboration with your hospital) to raise awareness for breastfeeding and substantiate your arguments by referring to the related standards (e.g. '[Promotion of breastfeeding](#)')
- **World Lung Day** (25 September): Raise awareness for the risks, prevention, and treatment of respiratory infections like respiratory syncytial virus (RSV) and consequences of preterm birth like bronchopulmonary dysplasia (BPD) and the need of follow-up, especially for preterm born and ill babies. Share links to the standards related to respiratory infections, like the standard on '[Respiratory outcome](#)', on your social media accounts
- **World Sight Day** (10 October): Use the awareness day to share information about the eye disease retinopathy of prematurity (ROP) that preterm babies are at risk to develop and promote the eye-health related standard on the '[Prevention, detection, documentation, and treatment of retinopathy of prematurity \(ROP\)](#)' and prepare a news article for your website on latest research or an expert advice in this field
- **World Hand Hygiene Day** (5 May)/**Global Handwashing Day** (15 October): Organise a 'handwashing event' in your local hospital, a public building, or a shopping mall, to raise awareness for (hand) hygiene. You can hand out information (e.g. flyers) with instructions on proper handwashing by referring to the standard on '[Hand hygiene](#)' and also see EFCNI's campaign '[Wash your hands – it's easy](#)' at [www.efcni.org](http://www.efcni.org). As hand hygiene is an important mean to prevent an RSV infection, you can use this connection to make people aware of the start of the RSV season and share information on the prevention and treatment of RSV (e.g. EFCNI factsheet on RSV available at <https://www.efcni.org/activities/downloads/>), referring to website content and selected standards (e.g. standard on '[Respiratory outcome](#)')



## NOTE

To get the link to the above mentioned standards, please go to the website [www.newborn-health-standards.org](http://www.newborn-health-standards.org) and enter the title of the standard in the 'Search' field. You will immediately find the standard you are looking for.



### NOTE

Many awareness days can easily be combined with your communication about one of the broader topics of the campaign 11 Months – 11 Topics, e.g. celebrate World Breastfeeding Week within the monthly topic of nutrition (August) (see this chapter: [Use awareness days for your promotion](#)).

Here are some practical recommendations for your general communication activities to use awareness days to promote the standards and the Call to Action for Newborn Health in Europe:

- Select the awareness days you want to promote early in advance and include them in your communication plan (see [Appendix: Communication plan](#))
- Organise an event related to the standards on the occasion of an awareness day
- Publish a social media post related to the standards using the official awareness days' materials and express your support of the awareness day in line with your organisation's aims
- Publish an information brochure related to the awareness day (e.g. a brochure about breastfeeding or a translation of the information brochure of the European Standards of Care for Newborn Health)
- Raise awareness and provide information for parents about a disease that can affect preterm and ill babies and that is featured in the standards (e.g. Respiratory Syncytial Virus - RSV or Retinopathy of Prematurity - ROP)
- Publish a press release (see this chapter: [Press and media](#)) about the standards and the Call to Action for Newborn Health in Europe related to the awareness day
- Use an awareness day for fundraising: for example, start a call for donations on Kangaroo Care Awareness Day (15 May) to support a training for healthcare professionals in line with the standards on infant- and family-centred developmental care



### NOTE

Joining a global movement makes your communication even more powerful. Align your communication (e.g. a campaign) with the awareness day campaign's annual motto (if available), using the official campaign materials, wording and hashtags.

## Live communication

### Personal meetings



#### *How can personal meetings support your communication*

Also in the digital age, face-to-face meetings remain key success factors. You can use personal meetings with key opinion leaders (KOLs), the media, and relevant target groups to inform about and raise awareness for the standards and the Call to Action for Newborn Health in Europe. In order to be well prepared for such options, always have some informative materials like the Call to Action for Newborn Health in Europe leaflet or the information brochure with you, as well as the key information about the project. These options might come by chance from time to time and these personal discussions bring you sometimes much further!

#### *What kind of events can you organise to communicate about the standards and the Call to Action for Newborn Health in Europe?*

- Face-to-face meeting with politicians of your constituency
- One-to-one discussions with key opinion leaders from your country
- Small discussion roundtables

### Public events



#### *How can public events support your communication?*

Next to personal meetings, another possibility for live communication is to organise a public event (e.g. a political event at your local parliament) or to present the standards at national and international conferences and congresses to a broader audience.



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### *Plan and host an event*

You might want to host an event with a focus on the standards on the standards in your country, e.g. a political event, or you would like to organise a hospital visit with journalists or politicians. If you do so, it is important that you involve the media to make them aware of the standards and the Call to Action for Newborn Health in Europe. As multipliers, they have the ability to spread your messages among a vast target group.

Involve the press in every step and announce your plans and activities well on time to them. Make sure your country/region/local area knows about what you do, who you are, and the event(s) you are planning.

Consider the following steps:

- Think about which information and which interview partners might be of value for your local/regional/national media
- Good interview partners for the media could be ex-preterm babies, parents, healthcare professionals, chair or board members of your organisation, or persons of interest. Choose persons from your organisation and possibly also parents willing and able to talk about their story
- Please note that whatever option you choose, you always have to have detailed written information about your organisation, the standards, the Call to Action for Newborn Health in Europe, and your event prepared for the media
- Develop a schedule for contacting journalists: Send your press release a few days in advance. A couple of days before your event call the respective journalists and share your story. Act sensitively when following-up
- Don't forget to contact online media and blogs. Compile lists with Twitter names of some of the journalists and send them direct tweets with the information about the preterm birth situation in your country, your activity, and event



#### NOTE

For further information, please go to this chapter: [Press and media](#).

### *During your event*

Provide some printed press releases and/or USB sticks, information about your organisation, about the European Standards of Care for Newborn Health project and the developed standards. You can also bring along the Call to Action for Newborn Health in Europe translated into your language. Someone in your group should be a media contact at the event and approach and keep track of the media, introduce themselves and offer to connect key spokespeople (members of the board for example) to the media as people to interview.

Social networking is important: In the course of the event, report about it 'in real time' on social media (e.g. by sharing news in your Instagram story, sharing pictures of the participants (given their approval) or statements about the event), see also this chapter: [Social media](#).

### *After your event*

Thank the media representatives within 24 hours after your event for attending your event or for publishing your information. This helps you to keep in contact and to establish a long-lasting relationship. Compile a media review about your activities and we would be very grateful to hear about your activities and success. Please send us some information about your event to: **[standards@efcni.org](mailto:standards@efcni.org)**.

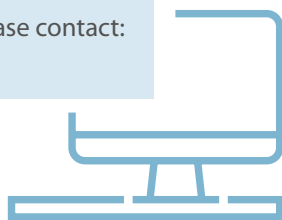
Keep an eye on the reactions about the event on your social media accounts. If there have been interactions or open questions, take the time to answer your follower's questions or thank them for sharing news about your event. Search for your keywords online, collect the links. Scan the written articles and collect them together with your links in a document. Use tools like Google alerts to get notifications if your organisation is mentioned in an online article.



#### NOTE

It is critical that all organisation members know that they have a contact person in your organisation to reach out to regarding the standards or the Call to Action. Therefore, make sure to provide your participants with contact points of reference. You can, for example, share a business card including the telephone number, and email address.

For questions or queries, please contact:  
[standards@efcni.org](mailto:standards@efcni.org).

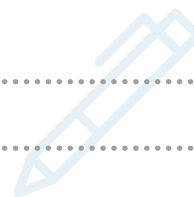


There are several materials and tools (e.g. a booth or roll-up with general information) that can complement the communication at your personal meetings and events. Learn more about these in chapter [Materials](#) and in chapter [How to get started: Stakeholder Mapping](#).



*Kick-off of the European Standards of Care for Newborn Health project in the European Parliament in Brussels in 2014 with politicians, representatives from healthcare societies as well as parent representatives.*

*From left to right: MEP Manfred Weber, MEP Dr Peter Liese, Silke Mader, Prof. Dr Berthold Koletzko, Prof. Dr Luc J. I. Zimmermann, MEP Rainer Wieland, MEP Prof. Dr Angelika Niebler, Prof. Dr Giuseppe Buonocore, Dr Eleni Vavouraki, Odile Frauenfelder*





CHAPTER

# Materials



# Materials

## Overview

- How to use the EFCNI materials
- The European Standards of Care for Newborn Health – the standards themselves
- Website
- Project report
- Information brochure
- Factsheet 'European Standards of Care for Newborn Health'
- Social media graphics
- PowerPoint presentation template
- Project videos
- Publications
- Call to Action for Newborn Health in Europe
- Factsheet 'Preterm birth'

Are your events and activities, promoting the European Standards of Care for Newborn Health – in the following 'the standards' – getting the attention they deserve? There is a variety of materials that EFCNI provides to support your activities to disseminate and implement the standards in your country.

In the following, you find further suggestions and examples of (communication) materials and tools together with explanations how you could use them to inform about the standards.

Consulting this toolkit, you will know more about:

- Different types of materials for different target groups
- How to use these materials to engage with your key stakeholder groups



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To download the communication materials, please go to:  
[www.newborn-health-standards.org/downloads](http://www.newborn-health-standards.org/downloads).



### NOTE

It depends decisively on your target group which materials you should use. Please have a look at the end of each chapter section, for which target group the materials are recommended. For further information on which stakeholders to approach, please go to chapter [How to get started: Stakeholder mapping](#).

## How to use the EFCNI materials

All EFCNI materials presented in the following are free of charge and can be used without asking permission as long as our copyright guidelines are observed. However, we would very much appreciate if you let us know in advance if, when, and how you use the materials. This also enables us to support your activity. Please contact us via [standards@efcni.org](mailto:standards@efcni.org).

### Copyright guidelines

A professional, up-to-date corporate design of the materials promoting the standards is incredibly important. When used consistently, this will have long-term benefits as it is the visual and international voice of the project. In addition, providing the materials is the work of many creative individuals and involves time and expenses for EFCNI.

Therefore, please note the following copyright guidelines for the appropriate use of the materials:



Do not alter the layout and design of the materials/templates (e.g. colour, type, composition) – it is what makes the standards distinctive and recognisable (see next paragraph).



Use any materials we offer only to raise awareness, for fundraising, and information. Do not use our materials for marketing or sales purposes of products or services.

X



EUROPEAN STANDARDS  
OF CARE FOR NEWBORN  
HEALTH

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care for newborn health



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care for newborn health



## NOTE

If you have any questions regarding the use of the copyright guidelines, do not hesitate to contact us via [standards@efcni.org](mailto:standards@efcni.org).

### *Translation of the materials*

Many of the materials by EFCNI presented in the following are available in several languages. You are very welcome to share the translated versions provided at [www.newborn-health-standards.org/downloads](http://www.newborn-health-standards.org/downloads).

If the materials you would like to use are not available in your national language yet, please get in touch with EFCNI. All promotion materials can be translated into your language, but please make sure to contact us via [standards@efcni.org](mailto:standards@efcni.org) before you start translating. There is a certain procedure that must be complied with to ensure the quality of the translations.



## NOTE

#### Translation of the standards

Please note that there are particular recommendations regarding the translation of the standards (see chapter: [The European Standards of Care for Newborn Health – the standards themselves](#)).

#### Translation of further EFCNI materials

- We are happy to provide you with translation templates and assist you with the translations
- Be aware that for every translation we need to ensure that the content is correct. Therefore, a medical editor has to be consulted who confirms that the translation is accurate
- The design of the translated materials has to be done by EFCNI. Make sure to plan sufficient lead time by contacting us early in advance, especially, if you need the material printed for a specific event. Depending on the content and quantity of the material, it may take minimum three months from first contact until you will receive and can print the final version
- When translating the content, you may adapt the content so that it fits to your country situation. However, we kindly ask you to stick to the original version as much as possible and do not change the design provided in the original versions by EFCNI



## NOTE



## The European Standards of Care for Newborn Health – the standards themselves

Being the fruit of the hard work by committed healthcare experts, parent and patient representatives, and further key stakeholders, **the standards themselves are the most important materials** for your activities. Make sure to always name the standards and reference where to find them ([www.newborn-health-standards.org](http://www.newborn-health-standards.org)) in all your communications, presentations, events, etc. When referring to the standards, you can take the following approaches:

- Download every standard separately
- Choose from selected standards 'in brief' with information about the standard at a glance, e.g. '[Maternal transfer for specialist care](#)'
- Download full sets of standards for each of the eleven main topics (e.g. [Birth and transfer](#), [Medical care and clinical practice](#)...), these are available at the overview pages for each topic (example: [www.newborn-health-standards.org/standards/birth-transfer/overview](http://www.newborn-health-standards.org/standards/birth-transfer/overview))
- Compile all standards together to get a comprehensive document of more than 600 pages
- To get an overview of the variety of topics of the around 100 standards, please see chapter [Background information: Statements of standards](#)



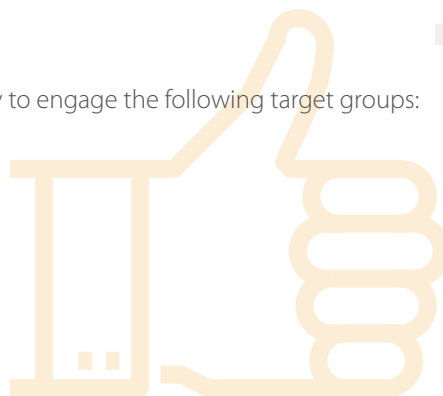
### NOTE

To get to the standards, please go to the website [www.newborn-health-standards.org](http://www.newborn-health-standards.org) and enter a topic (keyword) you are interested in 'Search field'. All standards related to this topic will be displayed immediately.

### Recommended usage

The standards themselves are a useful tool especially to engage the following target groups:

- Healthcare professionals and medical societies
- Industry representatives
- Media
- Parent, patient, and advocacy groups
- Payors
- Policy makers and parliamentarians





## NOTE

**Translation of standards:** If you consider translating the standards into your language, please keep in mind that a translation word by word does not make always sense. When we talk about translating the standards, it means that the standards need to be adapted to the individual country situation. This needs to be done within national expert meetings (see chapter [How to get started](#)). We also recommend not to translate the full standards document, but to start with the standards information brochure (see this chapter: [Information brochure](#)). Use this brochure to define the most pressing needs in your country and then to translate the standards.

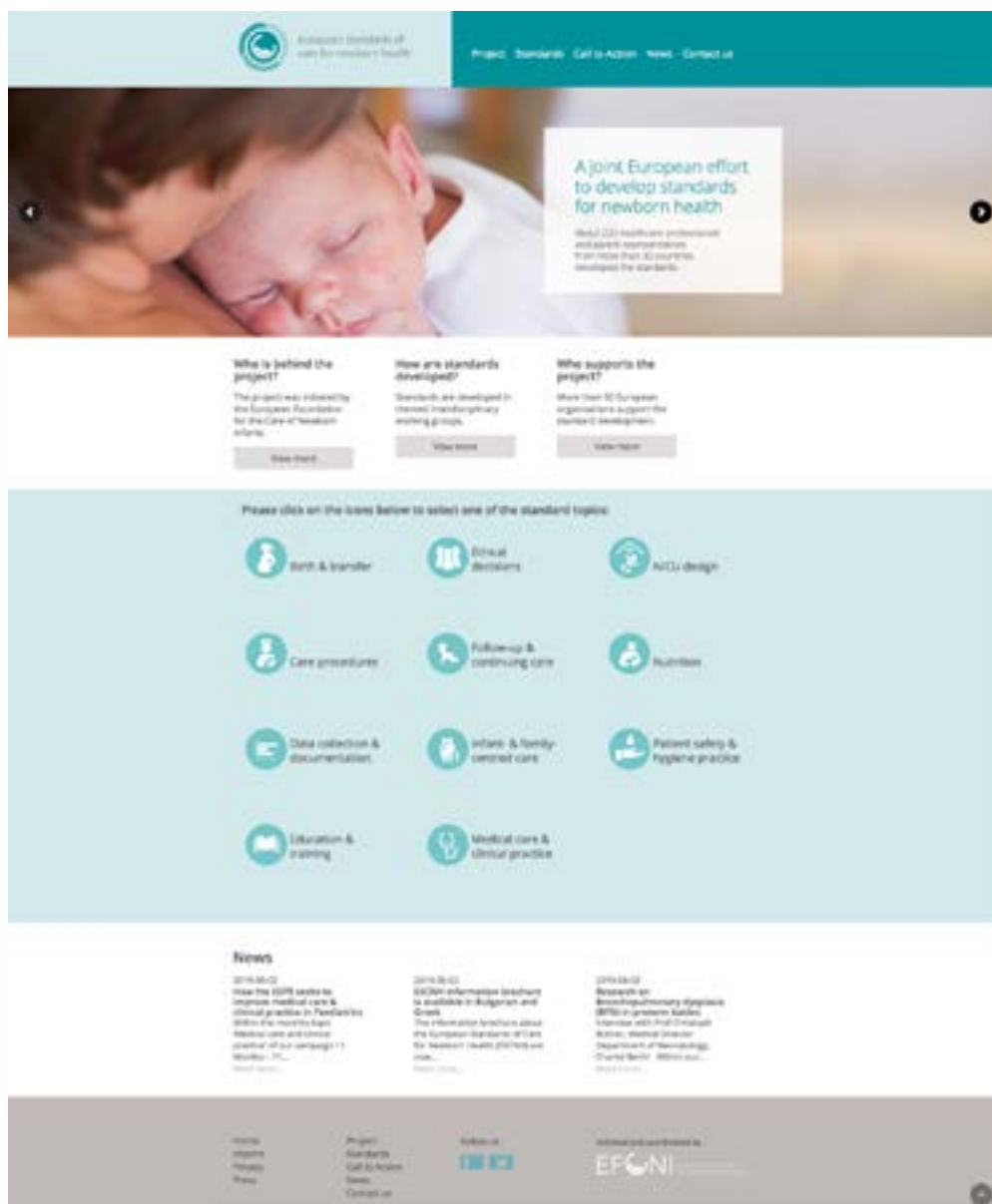
Please get in touch with us via [standards@efcni.org](mailto:standards@efcni.org) if you wish to translate parts of the standards into your language. We can counsel you what makes the most sense to be translated.

# Website

The website of the standards [www.newborn-health-standards.org](http://www.newborn-health-standards.org) does not only provide the standards but also is the main source of information for external parties who want to gain information but also for those who are actively involved in the project, e.g.:

- Your events and activities can be listed in the website's news section
- You can use the website as a reference when linking to it in your own articles or social media posts
- It also offers you up-to-date content about the implementation of the standards

The website can serve as a tool to disseminate the standards. For more advice on how to use the standards website as a means of implementation of and support for the standards, see chapter [Communication: Website](#).





## Project report

If you are looking for more detailed information about the project and the standards, the project report about the European Standards of Care for Newborn Health is the right source of information for you. It is a reference document on the project's history, the methods, the development of the standards, and the experts involved.

The project report will give you:

- A detailed overview and background information about the project itself
- An overview of the standard topics covered by each Topic Expert Group
- An aid to decision-making when defining the standards to start with in your country

### Project report



### NOTE

To download the project report about the European Standards of Care for Newborn Health, please go to: [www.newborn-health-standards.org/downloads](http://www.newborn-health-standards.org/downloads).

### Recommended usage

The project report on the European Standards of Care for Newborn Health is a useful tool especially for the following target groups:

- Healthcare professionals and medical societies
- Industry representatives
- Payors
- Policy makers and parliamentarians



## Information brochure

The information brochure on the European Standards of Care for Newborn Health project provides more detailed information on the project and the standards. It also gives an overview of the eleven overarching topics, neonatal care was divided into. Each one of them corresponds to a Topic Expert Group (i.e. the group of experts working on a specific topic).



### NOTE

To download the information brochure on the European Standards of Care for Newborn Health project in different languages, please go to: [www.newborn-health-standards.org/downloads](http://www.newborn-health-standards.org/downloads). If your language is missing and you would like to have the translation, please see this chapter: [How to use the EFCNI materials](#).

The information brochure provides you with:

- Detailed information on the project, the topics, and the standards: due to the convenient size of the booklet, you can bring it with you to congresses and meetings to hand it out to interested persons
- A useful overview when defining those standards to start with in your country
- A source of information for stakeholders who already know about the project and the standards and who would like to receive more detailed information



Information brochure

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### Recommended usage

The information brochure on the European Standards of Care for Newborn Health project is a useful tool especially for the following target groups:

- Healthcare professionals and medical societies
- Industry representatives
- Policy makers and parliamentarians



## Factsheet 'European Standards of Care for Newborn Health'

The factsheet 'European Standards of Care for Newborn Health' is extremely useful if you want to introduce the standards to persons who have very little time and need to be briefly informed about the standards and the project as such.

The factsheet 'European Standards of Care for Newborn Health':

- Gives a short overview of the project and its aims
- Provides all important information at a glance
- Is an easy and quick read
- Fits every briefcase and can easily be carried with you (for meetings, conferences, etc.)



### NOTE

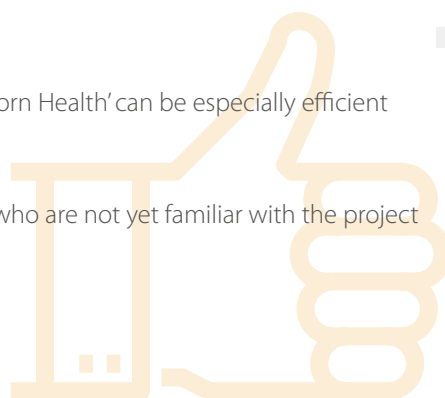
To download the factsheet 'European Standards of Care for Newborn Health', please go to: [www.newborn-health-standards.org/downloads](http://www.newborn-health-standards.org/downloads).

**Factsheet 'European Standards of Care for Newborn Health'**

### Recommended usage

The factsheet 'European Standards of Care for Newborn Health' can be especially efficient with the following target groups:

- Healthcare professionals and medical societies who are not yet familiar with the project
- Hospital administrators
- Industry representatives
- Payors
- Politicians



## Social media graphics

In chapter [Communication: Social media](#), we give advice on how to promote the standards and your corresponding activities on your social media accounts. For this purpose, you can choose from several social media graphics to share on your accounts. Here are some examples:

- Social media graphics of the 11 Months – 11 Topics campaign by EFCNI (e.g. topic announcement, light-house projects, etc.), see examples of available graphics below and further information in chapter [Communication: Campaigning](#) and chapter [Background information: Statements of standards](#)
- Social media graphics of the Call to Action for Newborn Health in Europe, see examples of graphics available at [www.newborn-health-standards.org/downloads](http://www.newborn-health-standards.org/downloads)



Social media graphics of the 11 Months – 11 Topics campaign

© EFCNI

- Social media graphics of the Call to Action for Newborn Health in Europe, see examples of graphics available at [www.newborn-health-standards.org/downloads](http://www.newborn-health-standards.org/downloads)



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Social media graphics of the Call to Action for Newborn Health in Europe

- External social media graphics related to the topics of the standards (e.g. social media graphics for different campaigns (e.g. on hand hygiene) by the [World Health Organization \(WHO\)](https://www.who.int)<sup>1</sup>, materials for campaigns like [World Breastfeeding Week](http://worldbreastfeedingweek.org)<sup>2</sup> by the World Alliance for Breastfeeding Action (WABA), the [Neonatal Mental Health Awareness Week](http://www.leosneonatal.org) by Leo's Neonatal<sup>3</sup>, etc.)

**Social media graphic by the World Health Organization (WHO):**



© Leo's Neonatal



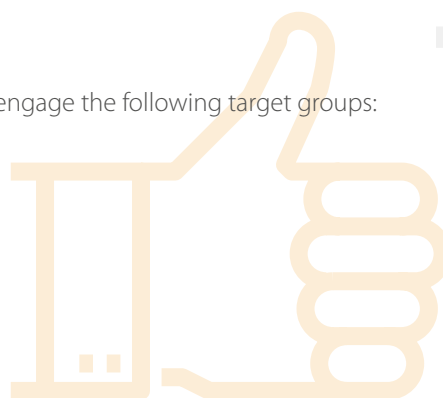
© World Health Organization (WHO)

**Social media graphic by Leo's Neonatal:**

**Recommended usage**

Social media graphics are a useful tool especially to engage the following target groups:

- Media
- Parent, patient, and advocacy groups
- Policy makers and parliamentarians
- The general public



<sup>1</sup><https://www.who.int> (go to the WHO website section 'Health topics', choose a topic and select from the available infographics)

<sup>2</sup><http://worldbreastfeedingweek.org>

<sup>3</sup><http://www.leosneonatal.org/neonatal-mental-health-awareness-week/get-involved/>



NOTE

Download EFCNI's social media graphics at [www.newborn-health-standards.org/downloads](http://www.newborn-health-standards.org/downloads) and check this website for regular updates. If you cannot find the materials you are looking for, please contact us via [standards@efcni.org](mailto:standards@efcni.org).



## PowerPoint presentation template

We warmly invite you to promote and support the standards when you are giving a talk or a presentation. Therefore, we are happy to provide you with a PowerPoint template. It is a useful tool to introduce the standards, the topics, and the project at meetings and conferences. You can use these PowerPoint slides free of charge for your presentations about the standards.



### NOTE

Download the PowerPoint presentation template at [www.newborn-health-standards.org/downloads](http://www.newborn-health-standards.org/downloads). Make sure that you always use **the latest version** of the template for your presentation as regular updates are provided on the website.

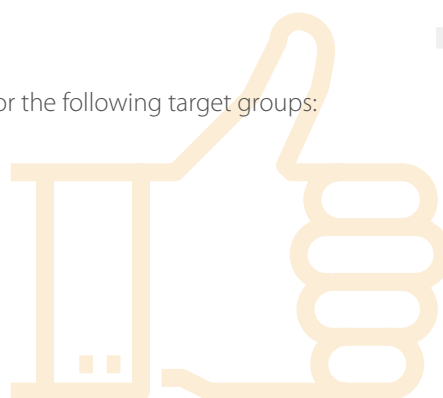
When using the PowerPoint presentation template, please note:

- ✓ In the comment field below each slide, you will find information about what is important regarding the respective slides
- ✓ You may translate the slides or change the order of the slides
- ✓ You do not have to show all slides, but you can choose from the provided template depending on the topic you are talking about and how much time you have
- ✓ You can also print the PowerPoint slides and use them as a folder during meetings with politicians or other stakeholders
- ✓ You can include data on maternal and newborn health for your country from the Euro-Peristat or from other sources for your country (see this chapter: [Excursus Euro-Peristat](#) and chapter [Background information: Supporting evidence base](#))

### Recommended usage

The PowerPoint template is a useful tool especially for the following target groups:

- Healthcare professionals and medical societies
- Industry professionals
- Parent, patient, and advocacy groups
- Payors
- Policy makers and parliamentarians







PowerPoint presentation template



## NOTE

Please send the final version of your presentation together with a picture of you during your presentation to: [standards@efcni.org](mailto:standards@efcni.org). By sending these documents, we assume your consent for saving it in our archive in order to track the outreach and to promote your event via our social media channels.

## Project videos

Some people think rather visually. In this case, our project video and the expert videos are the right choice for you to convince them about the need of the standards. The videos can also help transport more emotional than just factual information.

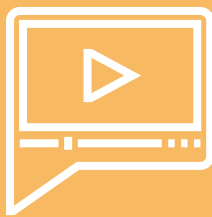


In addition, we provide videos of some of the Topic Expert Group Chairs involved in the development of the standards.



The videos are a helpful tool if you want to:

- Share audio-visual comprehensive information about the standards and the project
- Give an introduction to the project
- Provide a variety of media and change from the mostly text-based information about the standards
- Provide an (emotional) break from text-based information



**If you want to use the videos for promotion or simply would like to learn more about the standards and the project:**

- Please watch the project video at: <https://youtu.be/vXVY7uVcn3w>
- Please watch the expert videos at: <https://www.youtube.com/user/EFCNIwecare/> (e.g. <https://youtu.be/f0UM70Tpudl>)

### Recommended usage

The videos are useful tools especially for the following target groups:


- Healthcare professionals and medical societies
- Industry representatives
- Media
- Parent, patient, and advocacy groups
- Payors
- Policy makers and parliamentarians
- The general public



## Publications

Besides the videos and other template materials, there are several publications about the standards and the project. We are very delighted and thankful that the standards have been featured in scientific journals like *The Lancet* and the *The Lancet Child and Adolescent Health*.





Editorial. The unfinished agenda of preterm births. *The Lancet*. 2016;388(12). Available from: [www.doi.org/10.1016/S0140-6736\(16\)32170-5](http://www.doi.org/10.1016/S0140-6736(16)32170-5)

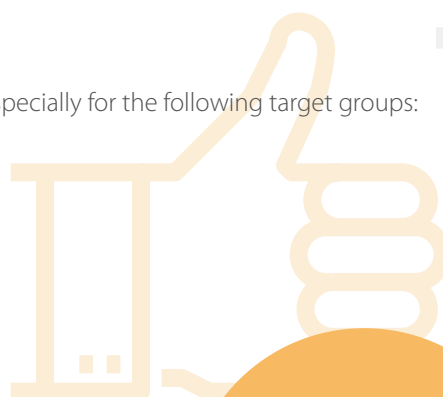
Editorial. Putting the family at the centre of newborn health - *The Lancet Child & Adolescent Health*. 2019;3(1). Available from: [www.doi.org/10.1016/S2352-4642\(18\)30369-9](http://www.doi.org/10.1016/S2352-4642(18)30369-9)

Mushtaq A, Kazi F. Family-centred care in the NICU. *The Lancet Child & Adolescent Health*. 2019;3(5):295–6. Available from: [www.doi.org/10.1016/S2352-4642\(19\)30089-6](http://www.doi.org/10.1016/S2352-4642(19)30089-6)

### Recommended usage

The publications on the standards are useful tools especially for the following target groups:

- Healthcare professionals and medical societies
- Industry representatives
- Media
- Parent, patient, and advocacy groups
- Payors
- Policy makers and parliamentarians



You are welcome to help spread these publications, by sharing and citing them within your network.

### *Further materials*

Furthermore, there are additional materials like roll-ups, ceiling banners, etc. about the European Standards of Care for Newborn Health tailored for special events (e.g. exhibitions at congresses). We are continuously extending our offer of materials and translations for the promotion and implementation of the standards. For an overview, please check [www.newborn-health-standards.org/downloads](http://www.newborn-health-standards.org/downloads) for regular updates.



## Call to Action for Newborn Health in Europe

As mentioned in chapter Advocacy on EU and national level: Call to Action for Newborn Health in Europe, the Call to Action for Newborn Health in Europe – in the following ‘the Call to Action’ – requires that European and national policy makers, hospital administrators, insurers, professional and patient associations, as well as industry should work together to bring the standards into practice and to ensure quality, equity, and dignity for the smallest patients.

It is a strong tool to mobilise people to support the standards also on a national level and can be used in several different ways. The following materials help you to promote the Call to Action in your country:

- Brochure on the Call to Action in Europe in 20 languages (status: September 2019)
- Social media graphics on the 14 key demands of the Call to Action, available in 20 languages (status: September 2019)



### NOTE

Learn more about the key demands of the Call to Action at [www.newborn-health-standards.org/call-to-action/](http://www.newborn-health-standards.org/call-to-action/) and download the Call to Action materials at [www.newborn-health-standards.org/downloads](http://www.newborn-health-standards.org/downloads). Some materials, e.g. the translated Call to Action demands in separate graphics, are available only on request. Please let us know which materials you wish to receive via [standards@efcni.org](mailto:standards@efcni.org).



© EFCNI

Call to Action flyer

## CHAPTER I Materials

Easy steps to promote the Call to Action for Newborn Health in Europe in your country:

- ✓ Tailor the Call to Action to your country: What is the most pressing need in your country? Select the most relevant demand or at least start with this demand
- ✓ Check at [www.newborn-health-standards.org/downloads](http://www.newborn-health-standards.org/downloads) if the Call to Action for Newborn Health in Europe brochure and social media graphics are available in your language. If yes, then download and use it! If not, then get in touch with us via [standards@efcni.org](mailto:standards@efcni.org) regarding the translation into your language
- ✓ Take a picture of yourself and, if possible, of further supporters (e.g. politicians, celebrities, healthcare professionals, industry representatives...) of the Call to Action while holding the Call to Action brochure in your/their hands, either in English or in your national language; if you do not have a printed copy of the brochure, you can easily download the cover of the brochure here [www.newborn-health-standards.org/downloads](http://www.newborn-health-standards.org/downloads) and use the printout instead
- ✓ Share the photo and other Call to Action materials in English or in your language and the picture via your website, newsletter and/or social media channels with your network
- ✓ Send the Call to Action brochure to members of the government or to all hospitals in your country together with pictures and personal stories
- ✓ Print out the photos of your Call to Action supporters in poster size and create an exhibition with a 'Wall of Supporters'
- ✓ Write a statement (see example) why you/your organisation supports the Call to Action

### Example

#### Call to Action statement

**Statement by Livia Nagy Bonnard from the parent organisation Melletted a helyem Egyesület, Hungary:**

*'I support the Call to Action, because every preterm baby has the right to get the best treatment and support for a healthy start in life and the best possible outcome.'*



*Image: Livia Nagy Bonnard from the organisation Melletted a helyem Egyesület (Hungary) with the Hungarian version of the Call to Action in her hands*





Print the Call to Action itself or create large posters, e.g. for a symbolic signing event. In this case, please get in contact with us: **standards@efcni.org** and we can send you the appropriate printing file



Download one or several social media graphics (see example) of the 14 Call to Action demands from the website **[www.newborn-health-standards.org/downloads](http://www.newborn-health-standards.org/downloads)**

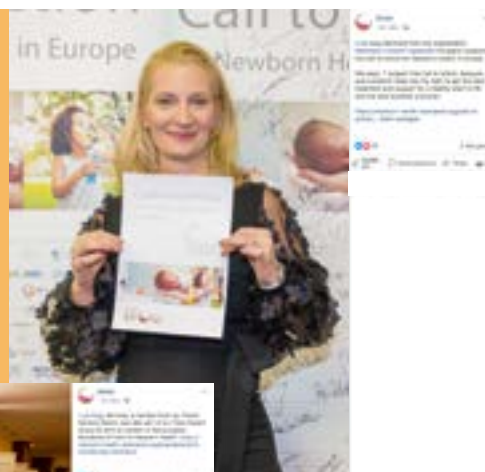
### Example



© EFCNI



Share your photo, the social media graphic, related hashtags (see chapter [Communication: Social media](#)) and the statement on your social media channels, on your website, in your newsletter or print it out as a poster



© EFCNI





Think about a petition in your country or use the Call to Action for Newborn Health in Europe when being in touch with your national politicians and journalists

This list does not claim to be exhaustive and serves as a guide; you are welcome to create and add your own supportive strategy.



Futher ideas...

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### NOTE

Whenever you promote the Call to Action for Newborn Health in Europe, always think about informing EFCNI via **[standards@efcni.org](mailto:standards@efcni.org)** as we can support your communication and can go viral! Your example will motivate others from ours and your network to follow your example!



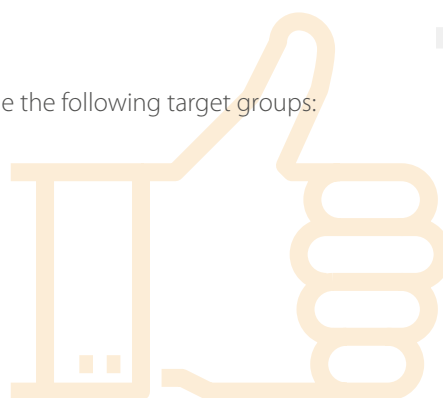


© EFCNI

### Recommended usage

The Call to Action is a useful tool especially to engage the following target groups:

- Healthcare professionals and medical societies
- Industry representatives
- Media
- Parent, patient, and advocacy groups
- Payors
- Policy makers and parliamentarians







For your inspiration: How can you involve further stakeholders?

Ask experts and politicians to support the Call to Action



© EFCNI



© EFCNI

Ask industry representatives to support the Call to Action



© Philips

Sean Carney, Chief Design Officer Royal Philips and Business Leader Healthcare Transformation Services, supports the Call to Action for Newborn Health in Europe:


'At Philips we are committed to delivering the next generation of care for parents and babies. I believe we need to do everything possible to give every child a healthy start in life and fully support the Call to Action for Newborn Health in Europe.'

## Factsheet 'Preterm birth'

The factsheet 'Preterm birth' gives concise information on preterm birth and thus, provides an excellent supporting evidence base (see more in chapter [Background information: Supporting evidence-base](#)). Please note that you should adapt the factsheet to your country to maximise the promotion and usage (e.g. by incorporating national statistics from the Euro-Peristat, find more information below).

The factsheet 'Preterm birth' will help you to:

- Have facts about preterm birth available for meetings and discussions with stakeholders
- Give stakeholders and interested persons information on preterm birth in general, which makes it easier for them to understand why the standards are important and needed



**Factsheet  
'Preterm birth'**

© EFCNI



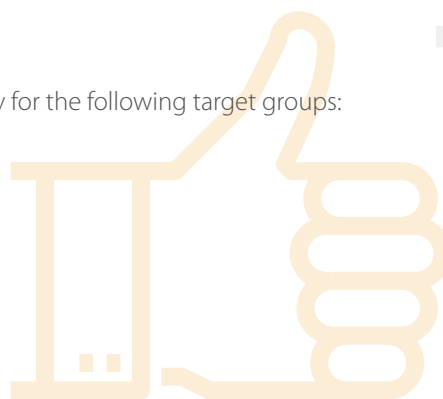
**NOTE**

To download the factsheet 'Preterm birth', please go to:  
**[www.efcni.org/activities/downloads/factsheets](http://www.efcni.org/activities/downloads/factsheets)**.

### Recommended usage

The factsheet 'Preterm birth' is a useful tool especially for the following target groups:

- General public
- Media
- Payors
- Policy makers and parliamentarians
- Parent, patient, and advocacy groups



In addition to the presented materials by EFCNI, there are further external sources of information that can be a valuable source of evidence to promote the standards.

### Excursus Euro-Peristat – a reliable source for health information:

Euro-Peristat is a European research project that aims to improve perinatal health. Please find more information about the project in chapter Background information: Supporting evidence base and via: **[www.europeristat.com](http://www.europeristat.com)**.



### Why and how to use the Euro-Peristat?

- Freely available source of high-quality scientific data on maternal and newborn health
- Available for most European countries (28 EU member states, Iceland, Norway, and Switzerland)
- Invaluable in order to have facts on the differences between countries
- To use with stakeholders/policy makers, to explain why changes in their country are needed
- Use the data and the tables/figures of the Euro-Peristat in your presentations in order to show in an easily comprehensible and impactful way why change/action is needed



### Wanted – your ideas:

If you have any suggestions for new materials to be created, please share your flash of inspiration with us via **[standards@efcni.org](mailto:standards@efcni.org)**.

For questions or queries, please contact: **[standards@efcni.org](mailto:standards@efcni.org)**.

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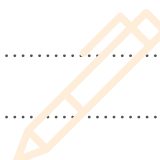
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CHAPTER

# Appendices





# Appendices

## Overview

- Appendix: Stakeholder mapping
- Appendix: A checklist for the meeting organiser
- Appendix: Invitation letter template for attending an expert meeting/roundtable
- Appendix: Introduction letter template for a politician
- Appendix: Thank you letter template for attending the expert meeting
- Appendix: Communication plan
- Appendix: Media release template



Appendix: Stakeholder mapping

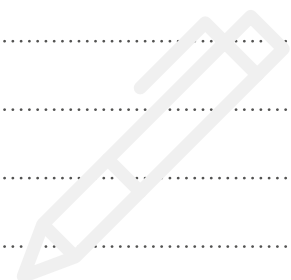
Excel worksheet of existing stakeholders and potential new partners							
Name of the organisation	Contact name (Title, name, surname)	Role	Position/ Job title	Assessment of the quality* of your existing relationship ranging from 1 - 5 where 1 is poor 2 is weak 3 is reasonable 4 is good 5 is excellent	Assessment of quality of influence the stakeholder has on others and/or of their potential to drive the preterm birth/newborn/ infant health agenda; ranging from 1 - 3 where 1 is low potential 2 is medium potential 3 is a high potential	Is preterm birth/new-born/infant health on their public agenda? Rank from 1 - 3 where 1 is not at all a priority 2 is a low priority 3 is a high priority	General comments
Healthcare professionals (e.g. nurses, midwives, neonatologists, etc.)							
Healthcare societies							
Parent organisations							
Policymakers (e.g. Ministry of health, local politicians, ...)							
NGOs, foundations, lobby associations, religious and ethical groups and communities							

\* An optimal relationship is supportive, loyal and trustworthy; please evaluate your current contacts critically to estimate the success of a possible partnership.

## Appendix: A checklist for the meeting organiser

Activity	Completed?	Target completion date
<b>Before the meeting</b>		
Identify participants and a moderator to lead through the meeting.		
Think about starting your meeting with a keynote lecture from a key opinion leader who is well accepted in the community.		
Identify and arrange the date and the venue in coordination with the stakeholders you are inviting to the meeting (e.g. via a doodle poll including three to four date proposals).		
Set up an agenda and coordinate it with the key opinion leader as well as the moderator.		
Draft a meeting request letter (see Appendix: Invitation letter template for a stakeholder).		
Clarify (internally) if you need contracts between the participants and your organisation.		
Send the meeting request letter together with the proposed agenda to all invitees timely.		
Prepare any additional materials and briefing information for the moderator and keynote speaker with suggested talking points.		
Be well prepared: Get to know as much as possible about the respective topic (do literature research, follow ongoing discussions within your network and healthcare professionals, read available guidelines).		
Prepare the PowerPoint slides with the content as a basis for the discussions in the meeting (the one who is responsible for the protocol writes all results down).		
Plan and organise further steps (dependent on objectives/results of the expert meeting and what will be agreed on during the expert meeting).		
Plan enough time for discussions.		
Share the final agenda with the participants early in advance as well as practical information (e.g. venue information, travel options) and ask if there is something missing what they would have expected.		
Confirm catering arrangements with the venue (coffee breaks or working lunch are good opportunities for informal talk and exchange).		
Identify and determine people who will internally and externally follow-up to the meeting (e.g. write the final strategy/document/further action points) and discuss already during the meeting, whether everyone is fine with it.		
<b>During the meeting</b>		
Prepare the room and the venue (signpost the way to the meeting room, provide place sets for participants, make sure the equipment is in place and that technical equipment works).		
Welcome all participants and distribute personal name badges.		
Explain the meeting rules and inform about the procedure and follow-up.		
Introduce the moderator and let him/her lead the discussion.		
Introduce the keynote speaker and the topic for the keynote lecture.		
Stick to the agenda and discuss everything on there but also be prepared to plan enough time for discussions.		
Document all the results transparently during the meeting (e.g. directly write down the results in your prepared PowerPoint slides via a beamer) so all participants can follow the discussion and everyone is up-to-date regarding the results of the discussions.		
Discuss potential cooperation/supporting partners with the participants, e.g. healthcare societies, parent organisations, third parties (this will help you to build up your strong national network, see this chapter: Building up a network in the field of preterm birth).		





## Appendix: Invitation letter template for attending an expert meeting/roundtable

[Insert the logo of  
your organisation]

[Your header: Name and postal address of your organisation]

[Name and postal address of the politician/key stakeholder]

[Date]

[Insert a catchy subject, e.g.: Kindly support for the European  
Standards of Care for Newborn Health]

Dear [insert title and name of the attendee],

On behalf of [insert name of your organisation] I would like to invite you to [insert name of the meeting]  
to work on the implementation of the European Standards of Care for Newborn Health in [insert your  
country].

This [meeting/roundtable] will bring in different key stakeholders to discuss the best possible way to  
promote our cause to [insert goal of meeting and explain with 2 or 3 sentences, e.g. it is our first step  
towards achieving our goal to implement the European Standards of Care for Newborn Health in our  
country. The key points from the discussion will be summarised into a position paper outlining the expert  
group's recommendations of how to put the standards into practice. Furthermore, we would like to discuss  
the potential next steps with you.]

The meeting will take place on:

[Date & location]

[Time]

[Preliminary Meeting agenda]

We would be delighted if you could join our project team and contribute to the discussions with your  
most valuable professional and personal experience.

Please send us [your reply mail/fax] by [time/date].

We are looking forward to your positive reply.

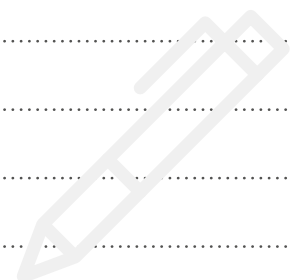
Yours sincerely,

[Insert title, your name and name of your organisation]

Possible content:



[This is an example for an invitation  
letter on the implementation of the  
standards, focusing on one specific  
standard topic. Please adjust the  
text in brackets to your respective  
meeting/topic/project, to your  
organisation's needs, and to the  
situation in your country!]





## Appendix: Introduction letter template for a politician

[Insert the logo of your organisation]

[Your header: Name and postal address of your organisation]

[Name and postal address of the politician/key stakeholder]

[Date]

[Insert a catchy subject, e.g.: Kindly support for the European Standards of Care for Newborn Health]

Possible content:

[Please adjust the text in brackets to the respective topic, to your organisation's needs, and to the situation in your country!]



Dear [insert exact title and name of the politician],

Thank you for the political leadership you provide for our [insert community/country]. As [a citizen/organisation] who is concerned about the general developments in health services, [I/we] value the role you play in shaping the policies that can lead to greater improvements for [our city, our country and our world]. However, we need to do more and that is why we need your support.

Today, it is my great pleasure to introduce the European Standards of Care for Newborn Health to you. Initiated by the European Foundation for the Care of Newborn Infants (EFCNI), the 96 standards available at [www.newborn-health-standards.org](http://www.newborn-health-standards.org) were developed by more than 220 leading experts from 35 countries – parent representatives, healthcare professionals, as well as further stakeholders from industry and NGOs. [Shortly present your organisation and also outline if and how your organisation has been supporting the standards, e.g. if you have been one of the experts who developed the standards or if your organisation endorsed the standards].

What makes this project outstanding is that patients – preterm and ill babies – represented by parent organisations, were involved in absolutely every step in the development of the standards. By bringing together people with similar objectives in the area of preterm birth, the standards will sustainably improve clinical care, policy and support for preterm and ill babies, and their families.

As you may already be aware, [insert the correct prevalence figure for your country e.g. 'one in ten babies is born preterm worldwide and the numbers are growing']. Being born early can affect these children's development. Not only do these challenges have an impact on children's health, but they also place a considerable burden on the child's family, our healthcare system, and wider society. So far, there have been no binding transnational guidelines or standards to ensure that preterm and ill babies have access to and receive the high-quality care they deserve and that parents get all the information and support they need.

The European Standards of Care for Newborn Health, therefore, suggest a number of practical steps that should be applied in hospitals in [insert your country] to improve health outcomes for preterm and ill babies. We believe this will make sure that the needs of vulnerable babies, their parents, and caregivers are prioritised and met, and give babies the best possible chance of living healthy, happy lives.

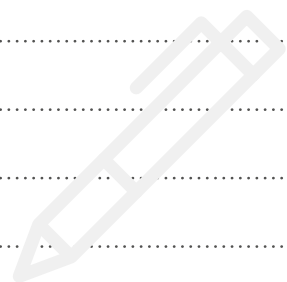
Bringing key stakeholders together to work on the implementation of the standards in [insert your country] is our first step towards achieving these ambitious goals. We would appreciate if you support our [Call to Action for Newborn Health in Europe](#) which has been signed by Members of the European Parliament and further key stakeholders. Your encouragement would support our cause in [specify Parliament/organisation/society]. Our organisation, friends and volunteers are taking this message out, but your voice would make all the difference. As you being a key person with a great interest in future developments in [Health/Society], we would very much welcome the opportunity to discuss the aims of this initiative with you and to explore further ways of working together on this important issue that has a vital impact on future generations.

I will, if I may, follow-up with your office to see if there may be an [opportunity to meet/organise a roundtable] in the coming weeks to discuss further details on how to improve the Standards in our country.

Thank you for your time and we are looking forward to meeting you.

Yours sincerely,

[Insert title, your name and name of your organisation]



## Appendix: Thank you letter template for attending the expert meeting

[Insert the logo of your organisation]

[Your header: Name and postal address of your organisation]

[Name and postal address of the attendee]

[Date]

[Insert a catchy subject, e.g. Expert meeting on the implementation of the European Standards of Care for Newborn Health]

### Possible content:



[This is an example for a thank you letter on the implementation of the standards, focusing on one specific standard topic. Please adjust the text in brackets to your respective meeting/topic/project, to your organisation's needs, and to the situation in your country! Try to be as precise as possible!]

Dear [insert title and name of the attendee],

On behalf of [insert name of your organisation] we/I would like to thank you very much for attending the recent [insert name of the meeting] to work on the implementation of the European Standards of Care for Newborn Health in [insert your country]. We very much appreciated your valuable input and the thoughtful and productive discussion.

The meeting was a very positive first step towards ensuring that the correct measures are in place so that every preterm and ill baby is given the best possible chance of living a happy and healthy life. Attached you will find the protocol of the meeting [if applicable]. [Insert any other important information/further actions/what has happened since the meeting.]

Furthermore, the key points from the discussion will be summarised into a [insert name of the document, e.g. publication, position paper, press release] outlining the expert group's recommendations of how to put the standards into practice. We will communicate the draft via email by [insert date] in order for you to respond with your comments, queries, and amendments.

Regarding the following next steps, we will also update you and stay in touch [insert the next steps, which were agreed on in the meeting. In the following you will find some examples for potential next steps:

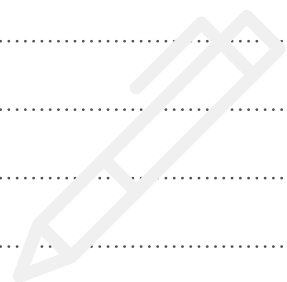
- Launch of the publication on a specific event, e.g. jENS Congress
- Development of a practical toolkit on that topic
- Development of a guideline or law change]

We look forward to receiving your feedback and continuing to work with you on putting the standards into practice by involving a wide group of healthcare professionals, service providers, parents, and advocacy groups with the aim of ensuring that preterm and ill babies and their families are given the high quality care and support that they need.

Thank you so much for your support and trust within this project!

Yours sincerely,

[Insert title, your name, and name of your organisation]



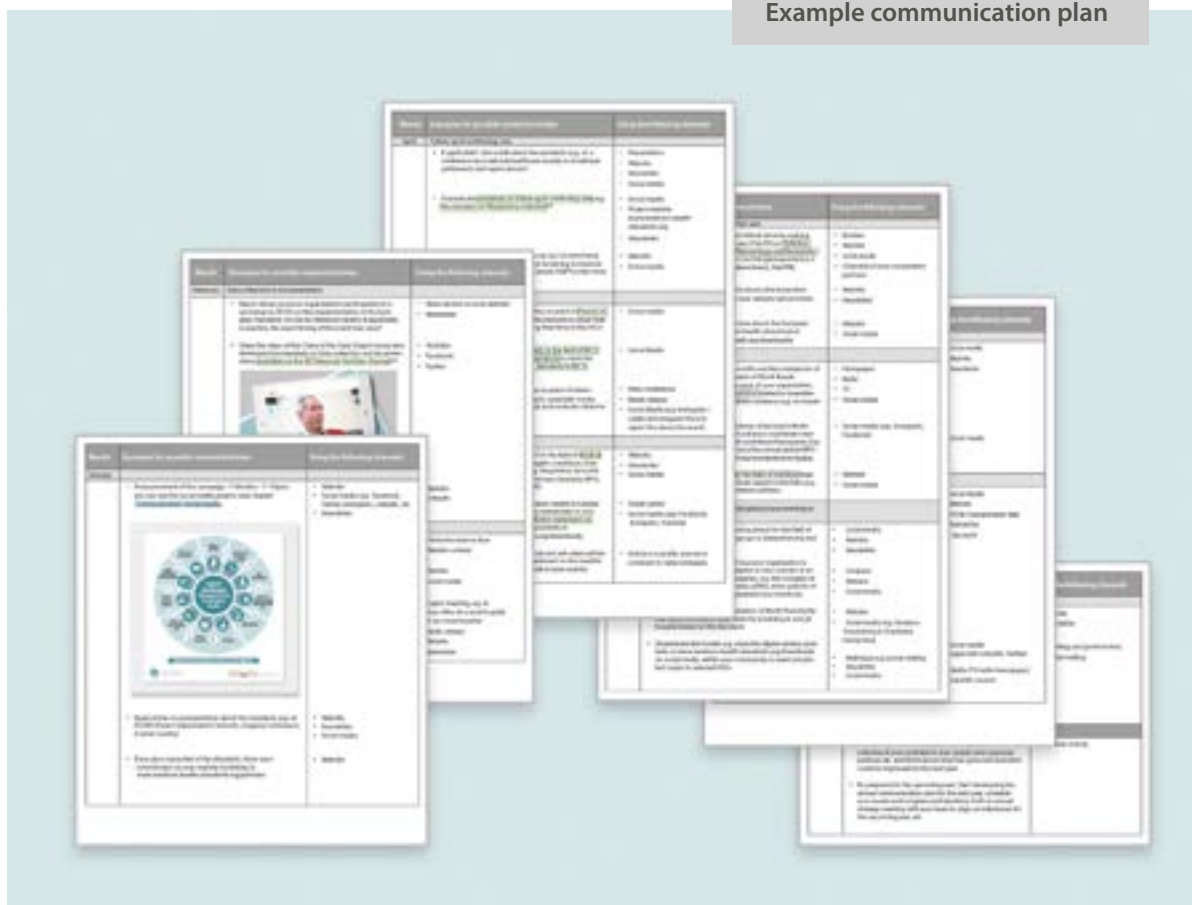
## Appendix: Communication plan

This communication plan template is a tool to plan your communication strategy to firstly raise awareness for the need of high quality newborn healthcare and secondly drive forth the implementation of high quality health standards in your country. The reference are the European Standards of Care for Newborn Health and the Call to Action for Newborn Health in Europe. Please note that this is an **example to give you some possible ideas and that you have to tailor the content according to your organisation's needs. The content also varies from year to year, depending on the events and activities taking place.** As it is a working document for your organisation, make sure to update it on a monthly and annual basis.

In chapter [Communication: Campaigning](#), we provide ready-to-use messages for the online and social media content suggested in this communication plan. As indicated in the template, we also recommend you to structure your communication corresponding to the monthly topics of the campaign 11 Months – 11 Topics (running from February until December; see chapter [Communication: Campaigning](#)), but you can also choose your own focus topics.

Besides the examples given in this toolkit, there are many other possibilities to promote the standards – unleash your imagination!


Example communication plan






## NOTE

If you have any questions regarding the use of the copyright guidelines, do not hesitate to contact us via [standards@efcnl.org](mailto:standards@efcnl.org).

Month	Examples for possible content/activities	Using the following channels
January	<ul style="list-style-type: none"> <li>Announcement of the campaign 11 Months – 11 Topics: you can use the social media graphic (see chapter <a href="#">Communication: Social media</a>)</li> </ul> 	<ul style="list-style-type: none"> <li>Website</li> <li>Social media: e.g. Facebook, Twitter, Instagram, LinkedIn, etc.</li> <li>Newsletter</li> </ul>
	<ul style="list-style-type: none"> <li>News article on a presentation about the standards (e.g. at EFCNI's Parent Organisations Summit, congress/conference in your country)</li> <li>If you are a supporter of the standards, show your commitment on your website by linking to <a href="http://www.newborn-health-standards.org/partners">www.newborn-health-standards.org/partners</a></li> </ul>	<ul style="list-style-type: none"> <li>Website</li> <li>Newsletter</li> <li>Social media</li> <li>Website</li> </ul>

Month	Examples for possible content/activities	Using the following channels
February	<b>Data collection &amp; documentation</b>	
	<ul style="list-style-type: none"> <li>Report about you/your organisation's participation in a workshop by EFCNI on the implementation of the European Standards of Care for Newborn Health (if applicable, in practice, the exact timing of the event may vary)*</li> <li>Share the video of the Chairs of the Topic Expert Group who developed the standards on Data collection and documentation (available on the <a href="#">EFCNIwecare YouTube channel</a>)**</li> </ul>  <ul style="list-style-type: none"> <li>Share research news about Data collection and documentation, e.g. about the EU-funded project RECAP preterm (Research on European Children and Adults born Preterm); view more at <a href="http://www.efcni.org/recap">www.efcni.org/recap</a></li> </ul>	<ul style="list-style-type: none"> <li>News section on your website</li> <li>Newsletter</li> <li>YouTube</li> <li>Facebook</li> <li>Twitter</li> <li>Website</li> <li>LinkedIn</li> </ul>
March	<b>Birth &amp; transfer</b>	
	<ul style="list-style-type: none"> <li>Provide information materials on Birth and transfer (e.g. new content on your website, a new information booklet etc.)</li> <li>Present the standards in the field of Birth and transfer, e.g. by focusing on one selected standard 'in brief' like the standard on '<a href="#">Maternal transfer for specialist care</a>')**</li> <li>Organise an expert meeting in the field of Birth and transfer (or about the standards in general): (see chapter <a href="#">How to get started</a>) and communicate the outcome of the event to your local media</li> </ul>	<ul style="list-style-type: none"> <li>Printed booklet or flyer</li> <li>Website content</li> <li>Website</li> <li>Social media</li> <li>Expert meeting, e.g. at your office at a local hospital or at a local hospital</li> <li>Media release</li> <li>Website</li> <li>Newsletter</li> </ul>



Month	Examples for possible content/activities	Using the following channels
April	<b>Follow-up &amp; continuing care</b>	
	<ul style="list-style-type: none"> <li>• If applicable*: Give a talk about the standards (e.g. at a conference by a national healthcare society or at national parliament) and report about it</li> <li>• Promote the <u>standards on follow-up &amp; continuing care</u>, e.g. the standard on '<u>Respiratory outcome</u>'**</li> <li>• Focus on the importance of follow-up, e.g. by promoting the toolkit of the EU-funded project Screening to improve Health In very Preterm InfantS in Europe (SHIPS); view more at <a href="http://www.efcni.org/ships">www.efcni.org/ships</a></li> </ul>	<ul style="list-style-type: none"> <li>• Presentation</li> <li>• Website</li> <li>• Newsletter</li> <li>• Social media</li> <li>• Social media</li> <li>• Project website <a href="http://www.newborn-health-standards.org">www.newborn-health-standards.org</a></li> <li>• Newsletter</li> <li>• Website</li> <li>• Social media</li> </ul>
May	<b>NICU design</b>	
	<ul style="list-style-type: none"> <li>• Start a social media campaign on the occasion of <u>Parents of Premies Day</u>: ask your social media followers to share their stories on what helped most during their time in the NICU</li> <li>• Provide an overview of the <u>standards in the field of NICU design</u> (e.g. link to the <u>full set of standards</u> or share the overview of the <u>statements of the standards in NICU design</u>)**</li> <li>• Organise a press conference on the occasion of International Nurses Day: invite local experts, especially nurses, who work in line with the standards and motivate others to follow their example</li> </ul>	<ul style="list-style-type: none"> <li>• Social media</li> <li>• Social Media</li> <li>• Press conference</li> <li>• Media release</li> <li>• Social Media (e.g. Instagram / create an Instagram Story to report live about the event)</li> </ul>
June	<b>Medical care &amp; clinical practice</b>	
	<ul style="list-style-type: none"> <li>• Publish an interview with an expert in the field of <u>Medical care and clinical practice</u>, e.g. on health conditions of babies are treated for in the NICU, e.g. Respiratory Syncytial Virus (RSV), jaundice, bronchopulmonary dysplasia (BPD), or Retinopathy of Prematurity (ROP)</li> <li>• Support the Call to Action for Newborn Health in Europe: share a photo/video of you or a key stakeholder in your country together with the <u>Call to Action statement on Medical care and clinical practice</u> (available at <a href="https://newborn-health-standards.org/downloads">https://newborn-health-standards.org/downloads</a>)</li> <li>• Write an article for a scientific journal and ask a key opinion leader in your country to give a statement on the need for the implementation of the standards in your country</li> </ul>	<ul style="list-style-type: none"> <li>• Website</li> <li>• Newsletter</li> <li>• Social media</li> <li>• Poster (print)</li> <li>• Social media (esp. Facebook, Instagram, Youtube)</li> <li>• Article in scientific journal or comment in daily newspaper</li> </ul>

Month	Examples for possible content/activities	Using the following channels
July	<b>Ethical decision-making &amp; palliative care</b>	
	<ul style="list-style-type: none"> <li>Promote projects in the field of Ethical decision-making and palliative care, e.g. the project PaluTiN on <a href="#">Palliative Care and Grief Counseling in Perinatology and Neonatology</a> by the German Association Das frühgeborene Kind e.V. (available at <a href="http://bit.ly/Bundesverband_PaluTiN">http://bit.ly/Bundesverband_PaluTiN</a>)</li> <li>Provide information for parents about ethical decision-making and palliative care on your website and promote the new content</li> <li>Promote the information brochure about the European Standards of Care for Newborn Health (download at <a href="http://www.newborn-health-standards.org/downloads">www.newborn-health-standards.org/downloads</a>)</li> </ul>	<ul style="list-style-type: none"> <li>Booklet</li> <li>Website</li> <li>Social media</li> <li>Channels of your cooperation partners</li> <li>Website</li> <li>Newsletter</li> <li>Website</li> <li>Social media</li> </ul>
August	<b>Nutrition</b>	
	<ul style="list-style-type: none"> <li>Newspaper/radio/TV interview with you/the chairperson of your organisation on the occasion of World Breast-feeding Week: e.g. explain the work of your organisation, <a href="#">the standards in the field of nutrition</a> related to breastfeeding; make sure to provide reliable evidence (e.g. on breastfeeding rates)</li> <li>17 August: Share collage of pictures of last year's World Prematurity Day together with a share a countdown message e.g. '... only 3 months left until World Prematurity Day on 17 November...' and announce the annual global WPD motto (available at <a href="http://www.efcni.org/worldprematurityday">www.efcni.org/worldprematurityday</a>)</li> <li>Share a link to <a href="#">the standards in the field of nutrition</a> together with an article by a healthcare expert in the field (e.g. on human milk banks or parenteral nutrition)</li> </ul>	<ul style="list-style-type: none"> <li>Newspaper</li> <li>Radio</li> <li>TV</li> <li>Social media</li> <li>Social media (esp. Instagram, Facebook)</li> <li>Website</li> <li>Social media</li> </ul>
September	<b>Education &amp; training of the multidisciplinary team working in neonatology</b>	
	<ul style="list-style-type: none"> <li>Feature an example of an inspiring project in the field of education and training; for ideas go to <a href="http://www.efcni.org">www.efcni.org</a> and search for 'lighthouse project'</li> <li>Autumn is congress season: If you/your organisation is participating in a national congress in your country or an international conference or congress, e.g. the Congress of joint European Neonatal Societies (jENS), share a photo of you at the congress/of a presentation/your booth etc.</li> <li>Start a charity activity in preparation of World Prematurity Day: e.g. a tombola to raise funds for a training in a local hospital based on the standards</li> <li>Disseminate this toolkit, e.g. share the digital version (available at <a href="http://www.newborn-health-standards.org/downloads">www.newborn-health-standards.org/downloads</a>) on social media, within your community or send out printed copies to selected KOLs</li> </ul>	<ul style="list-style-type: none"> <li>Social media</li> <li>Website</li> <li>Newsletter</li> <li>Congress</li> <li>Website</li> <li>Social media</li> <li>Website</li> <li>Social media (e.g. Facebook 'Fundraising &amp; Charitable Giving' tool)</li> <li>Mailing(s): e.g. postal mailing</li> <li>Newsletter</li> <li>Social media</li> </ul>

Month	Examples for possible content/activities	Using the following channels
October	<b>Patient safety &amp; hygiene practice</b>	
	<ul style="list-style-type: none"> <li>In many regions, the RSV (respiratory syncytial virus) season starts in autumn; thus Healthy Lung Month, Global Hand-washing Day, and Lung Health Day are good opportunities to raise awareness for the importance of (hand-) hygiene to prevent respiratory infections like RSV:               <ul style="list-style-type: none"> <li>Link to EFCNI's campaign <a href="#">Wash your hands – it's easy</a> (target group: parents/families)</li> <li>Promote the <a href="#">standard on 'hand hygiene'</a> (target group: healthcare professionals)</li> </ul> </li> <li>Promote the Call to Action for Newborn Health in Europe: focus on the statement on Patient safety &amp; hygiene practice (free download of the graphic at: <a href="http://www.newborn-health-standards.org/downloads">www.newborn-health-standards.org/downloads</a>)**</li> </ul>	<ul style="list-style-type: none"> <li>Social media</li> <li>Website</li> <li>Newsletter</li> <li>Social media</li> </ul>
November	<b>Infant &amp; family-centred developmental care</b>	
	<ul style="list-style-type: none"> <li>Use 17 November - World Prematurity Day (WPD) as a key momentum to communicate about the standards, e.g.               <ul style="list-style-type: none"> <li>Share photos of events around the world related to the standards</li> <li>Promote your own WPD events with regard to the standards (e.g. a roundtable with experts)</li> <li>Share information and pictures about your event with EFCNI via <a href="mailto:worldprematurityday@efcni.org">worldprematurityday@efcni.org</a> to make it visible on the global website <a href="http://www.efcni.org/worldprematurityday">www.efcni.org/worldprematurityday</a></li> <li>Include your event in the EFCNI Changemaker Map at <a href="http://www.efcni.org/changemakermap">www.efcni.org/changemakermap</a></li> <li>Print a WPD poster and distribute it to your local hospitals (free templates at <a href="http://www.efcni.org/worldprematurityday">www.efcni.org/worldprematurityday</a>)</li> </ul> </li> <li>Share an overview of the standards in the field of <a href="#">Infant- and family-centred developmental care</a>*</li> <li>Give a TV/radio/newspaper interview or publish an article in a scientific journal in your country: Explain the standards and how they could affect the change in your country</li> </ul>	<ul style="list-style-type: none"> <li>Social Media</li> <li>Website</li> <li>EFCNI Changemaker Map</li> <li>Newsletter</li> <li>Live event</li> <li>Social media (especially LinkedIn, Twitter)</li> <li>Media (TV/radio/newspaper)</li> <li>Scientific journal</li> </ul>

Month	Examples for possible content/activities	Using the following channels
December	<b>Care procedures</b>	
	<ul style="list-style-type: none"> <li>Look for inspiring projects/activities by your partners in the field of care procedures and publish an article or an interview</li> <li>The holiday season traditionally is a good momentum to thank your network, corporate partners, collaboration partners, donors, and staff for their commitment for the implementation of the standards: Create, for example, special (digital or printed) thank you/seasonal cards and share a review of what you have achieved in your country with regard to the standards, as well as an outlook of your plans for the upcoming year</li> </ul>	<ul style="list-style-type: none"> <li>Website</li> <li>Newsletter</li> <li>Greeting card (print/online)</li> <li>Digital mailing</li> </ul>
Outlook		
	<ul style="list-style-type: none"> <li>Document and evaluate your efforts: Report the annual outcome of your activities to your project and corporate partners etc. and think about what has gone well and what could be improved for the next year</li> <li>Be prepared for the upcoming year: Start developing the annual communication plan for the next year, schedule your events and congress participations, hold an annual strategy meeting with your team to align on milestones for the upcoming year, etc.</li> </ul>	<ul style="list-style-type: none"> <li>Internal activity</li> </ul>

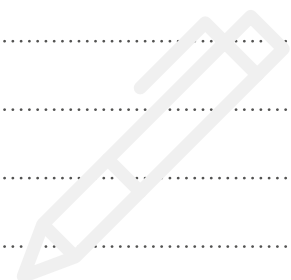


## NOTE

Do not forget to share your information with EFCNI in advance of the publication via [standards@efcni.org](mailto:standards@efcni.org) as we can support you in promoting your content.

\* The timing of this content may differ and take place in another month. Depending on the date of the meeting/ event, it may make sense to communicate about it at a later stage.

\*\* Recurring content which can be repeated every month; for more information, please have a look at the campaign website [www.efcni.org/11-months-11-topics](http://www.efcni.org/11-months-11-topics) and EFCNI's social media channels.



## Appendix: Media release template

[Insert the logo of your organisation]

[Insert a release date] (and time and/or embargo if needed)

[Insert headline] (Needs to be attention-grabbing)

[Insert body of text, considering the following aspects:]

The [insert name of your organisation] is supporting the European Standards of Care for Newborn Health and the Call to Action for Newborn Health in Europe. On the occasion of World Prematurity Day on 17 November [insert year], the [insert name of your organisation] organised a [insert type of meeting, e.g. round-table] of renowned experts in [insert topic] and parent representatives to work towards the implementation of the standards in [insert country]. The event called [insert title of the event] took place in [insert city].

*The first paragraph should include the most important information (who, what, where, when & why).*

As a result of the meeting, the participants developed [insert topic/next steps, e.g. an action plan for the first national follow-up programme for preterm and ill children].

[Insert further details and outcome of the meeting. Make sure to provide reliable numbers as well as direct quotes, e.g. by the Chair of your organisation, a local politician, an expert, etc.]

[The last paragraph should include the conclusion and an outlook on the next steps.]

[Insert contact information here including name, title, organisation, phone, email, and website]

Name

Title

Organisation

Phone number

E-mail

Website

Possible content:

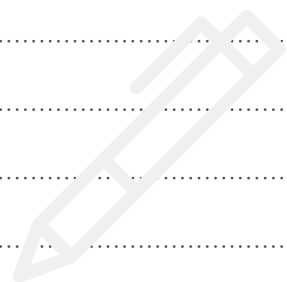


[This is an example on how to begin your media release. The basis for this template was the expert roundtable of the Bulgarian parent organisation Our Premature Children Foundation (OPCF). Please adjust the text in brackets to your organisation and respective news.]

### General recommendations:

- The length of the total media release should be kept to 1 page, maximum 2 pages
- Use a writing style that is direct and easy to read
- Point out the situation of preterm babies and their families in your country, based on a supporting evidence base
- Use direct quotes from reliable references
- Make sure you have the permission to use external sources and the correct copyright details (e.g. quotes, graphics, photos, etc.)
- Avoid using hyperbole, jargon, and acronyms
- Make sure your media release is 'newsworthy' and offers real news to journalists: consider the so called news value factors, like the right timing – e.g. on occasion of World Prematurity Day, the significance of your topic – e.g. the number of children in your country who could be saved or whose life could be improved by the implementation of the standards, etc. (search, e.g. via Google, for the key word 'news value' and you will find plenty of information online)
- Get others to proofread – the media release or parts of it may be directly adopted in a publication without too many modifications







# Supporting healthcare societies

We warmly thank the following healthcare societies and organisations for supporting the European Standards of Care for Newborn Health and endorsing the Call to Action for Newborn Health in Europe (in alphabetical order):





# Acknowledgement

Developing the European Standards of Care for Newborn Health would not have been possible without the invaluable support, expertise, and advice of all people involved in it: the Chair Committee and the Topic Expert Groups, consisting of (healthcare) experts from various disciplines, as well as parent representatives, the EFCNI Parent Advisory Board, the EFCNI Executive Board, the healthcare professional societies and parent organisations who have been supporting the development of the standards and now the standards themselves, the industry partners financing the project, and last but not least the whole EFCNI team.

## The Chair Teams and Topic Expert Groups (TEG)

We thank the following project members for their invaluable support, great work and contribution within the development of the European Standards of Care for Newborn Health.

### Birth & transfer



#### Chairs of the TEG

*Dr Dietmar Schlembach, Germany*

*Professor Umberto Simeoni, Switzerland*

#### Members of the TEG

Prof Annette Bernloehr, Germany

Dr Morten Breindahl, Sweden

Prof Irene Cetin, Italy

Dr Maurizio Gente, Italy

Dr Štefan Grosek, Slovenia

Dr Gilles Jourdain, France

Prof Franz Kainer, Germany

Dr Andrew Leslie, UK

Livia Nagy Bonnard, Switzerland

Asta Radzeviciene, Lithuania

Dr Nandiran Ratnavel, UK

Prof Rainer Rossi, Germany

Prof Matthias Roth-Kleiner, Switzerland

Prof Gerard A.H. Visser, The Netherlands

### Medical care & clinical practice



#### Chairs of the TEG

*Professor Luc Zimmermann, The Netherlands*

*Professor Lena Hellström-Westas, Sweden*

*Professor Giuseppe Buonocore, Italy*

#### Members of the TEG

Dr Kathryn Beardsall, UK

Prof Frank van Bel, The Netherlands

Dr James Boardman, UK

Dr Kajsa Bohlin, Sweden

Prof Maria Borszewska-Kornacka, Poland

Dr Jeroen Dudink, The Netherlands

Prof Mary Fewtrell, UK

Prof Andreas Flemmer, Germany

Prof Anne Greenough, UK

Prof Pierre Gressens, France

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Prof Egbert Herting, Germany

Prof Anton van Kaam, The Netherlands

Prof Claus Klingenberg, Norway

Prof Berthold Koletzko, Germany

Dr Rene Kornelisse, The Netherlands

Prof Boris Kramer, The Netherlands

Dr Gianluca Lista, Italy

Prof Rolf F. Maier, Germany

Dr Tuuli Metsvaht, Estonia

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Prof Eren Özek, Turkey

Dr Adelina Pellicer Martínez, Spain

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Prof Heike Rabe, UK

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Prof Mario Rüdiger, Germany

Prof Elie Saliba, France

Prof Ola Didrik Saugstad, Norway

Prof Andreas Stahl, Germany

Dr Michael Steidl, Germany

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Prof Henkjan Verkade, The Netherlands

Dr Eduardo Villamor, The Netherlands



# Acknowledgement

## Care procedures



### Chairs of the TEG

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*Odile Frauenfelder, The Netherlands*

### Members of the TEG

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Dr Fátima Camba, Spain  
Monica Ceccatelli, Italy  
Dorottya Gross, Hungary  
Ingrid Hankes-Drielsma, The Netherlands  
Eva Jørgensen, Denmark

Anna Kalbér, Germany  
Thomas Kühn, Germany  
Marianne van Leeuwen, The Netherlands  
Dr Maria López Maestro, Spain  
Elsa Silva, Portugal  
Xenia Xenofontos, Cyprus

## Infant- & family-centred developmental care



### Chairs of the TEG

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*Professor Pierre Kuhn, France*

### Members of the TEG

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Dr Inga Warren, UK

## NICU Design



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## Nutrition



### Chairs of the TEG

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*Professor Mary Fewtrell, UK*

### Members of the TEG

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Prof Hans van Goudoever, The Netherlands

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Dr Susanne Herber-Jonat, Germany  
Prof Alexandre Lapillonne, France

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Dr Peter Szitanyi, Czech Republic

## Ethical decision-making & palliative care



### Chairs of the TEG

*Professor Jos Latour, UK*  
*Professor Gorm Greisen, Denmark*

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Dr Laurence Caeymaex, France  
Dr Marina Cuttini, Italy

Prof Nicholas Embleton, UK  
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Dr Daniel Nuzum, Ireland  
Prof Jochen Peters, Germany

Karl Rombo, Sweden  
Yannic Verhaest, Belgium  
Dr Daniel Wood, UK

## Follow-up & continuing care



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Prof Mijna Hadders-Algra, The Netherlands  
Prof Christoph Härtel, Germany  
Prof Egbert Herting, Germany  
Dr Bregje Houtzager, The Netherlands  
Dr Britta Hüning, Germany  
Dr Shelley Hymel, Canada  
Dr Julia Jäkel, USA/Germany  
Prof Mark Johnson, UK  
Prof Samantha Johnson, UK  
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Dr Federico Prefumo, Italy  
Prof Alessandra Sansavini, Italy  
Dr Gert van Steenbrugge, The Netherlands

Dr Irma van Straaten, The Netherlands  
Dr Jacqueline UM Termote, The Netherlands  
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Dr Marie-Jeanne Wolf-Vereecken, The Netherlands



# Acknowledgement

## Patient safety & hygiene practice



### Chairs of the TEG

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### Members of the TEG

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## Data collection & documentation



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## Education & training of the multidisciplinary team working in neonatology



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**Babies born preterm do not only have a tough time during the first days or months of life. Preterm birth may affect us and our families for a lifetime.**



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**Lukas Mader, 22 years old,  
born at 25 weeks of gestation**



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abbvie

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Nestlé  
**Nutrition**Institute

**PHILIPS**  
**AVENT**

**PHILIPS**

*Takeda*

Thanks to Dräger for supporting the project from 2013 till 2015.

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“

A hero isn't always big and strong.  
A hero is simply one who has the  
strength and courage to  
overcome overwhelming  
circumstances.

Unknown

”

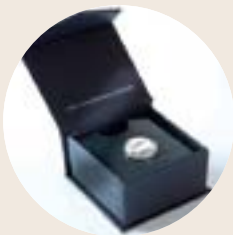
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# EFCNI donation programme



*Despeena, born at 24 weeks  
weighing 820 grams*

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# Imprint

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Visit us on     

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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 long-term health of preterm and newborn children. EFCNI's vision is to ensure the best start in life for every baby.

For more information: [www.efcni.org](http://www.efcni.org)

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Let them  
thrive!

