

Table 11 Standard "Parental involvement" public consultation comments

ID	Country	How would you rate the overall quality of the standard "Parental involvement"?	Do you have any recommendations on how to improve the standard "Parental involvement" (e.g. rational, benefits, components)?		Is there any important evidence or useful guidelines you would recommend to be included in the standard "Parental involvement"?		Do you think the standard "Parental involvement" is relevant in your country?		Do you have any conflict of interest (e.g. financial support or consulting of industry)?		Please specify if you are responding as an individual or on behalf of an organisation.
		Response	Response	Yes - Please make your recommendation(s) below.	Response	Yes - Please specify below, which evidence should be added (DOIs, references) to the standards and why.	Response	No - Please specify below why the standard is not relevant in your country.	Response	Yes - Please enter your conflict(s) of interest.	Response
1	Czech Republic		4	No		No		Yes		No	Individual
2	Poland		5	No		I don't know		Yes		No	Individual
3	Italy		4	Yes - Please make your recommendation(s) below.	Parental Involvement - Rational, Benefits, Components: include involve parents during painful procedures (non-pharmacological pain relief procedures) Psychological support is offered to parents	Yes - Please specify below, which evidence should be added (DOIs, references) to the standards and why.	Update the sources	Yes		No	Vivere Onlus
4	Germany		4	Yes - Please make your recommendation(s) below.	Include new literature on the role of fathers. Consider prenatal parental consultations	Yes - Please specify below, which evidence should be added (DOIs, references) to the standards and why.	Karii Treyvaud, Alicia Spittle, Peter J. Anderson, Karel O'Brien, A multilayered approach is needed in the NICU to support parents after the preterm birth of their infant, Early Human Development, Volume 139, 2019, 104838, ISSN 0378-3782, https://doi.org/10.1016/j.earlhumdev.2019.104838 .	Yes		No	Bundesverband Bunter Kreis
5	Portugal		5	No		No		Yes		No	Associação Portuguesa de Enfermagem Pediátrica e Neonatal
6	Italy		4	Yes - Please make your recommendation(s) below.	Considering the feeling of loneliness experienced by the parents during this pandemic, could we add how to manage parental involvement in an extremely "abnormal" situation?	Yes - Please specify below, which evidence should be added (DOIs, references) to the standards and why.	Shu Hui Chan, Shefaly Shorey. Healthcare professionals' sense of coherence of parental involvement in neonatal intensive care units: A framework synthesis. Nurs Health. 2021 Aug 19. doi: 10.1002/nur.22178. This recent qualitative article could be interesting.	Yes		No	Individual
7	Portugal		5	No		No		Yes		No	Portuguese Society of Neonatology
9	Estonia		5	No		No		Yes		No	Tartu University Hospital
10	Romania		5	No		No		Yes		No	ANMCS
11	Australia		4	No		No		Yes		No	Individual
12	Cyprus		5	No		Yes - Please specify below, which evidence should be added (DOIs, references) to the standards and why.	Neuroscience meets nurture: challenges of prematurity and the critical role of family-centred and developmental care as a key part of the neuroprotection care bundle Roopali Soni,1,2 Charlotte Tscherning Wel-Wel,1,3 Nicola J Robertson 4,5 This is a wonderful review of 2021 explaining in detail the neuroscience behind neurodevelopmental delays in premature babies and how active parenting in the NICU is the most essential neuroprotective strategy during a baby's stay in the NICU.	Yes		No	Thermokittitha Agapis
13	Poland		5	Yes - Please make your recommendation(s) below.	Components For neonatal units. Establishing procedurs decreasing the vulnerability of parents and newborns during pandemic. Organisation the role od parents in caring for their baby in hospital during pandemic. For hospital: Establish Discharge Newborn's Programe for parents.	Yes - Please specify below, which evidence should be added (DOIs, references) to the standards and why.	See above	Yes		No	Coalition for Premies
14	Czech Republic		4	Yes - Please make your recommendation(s) below.	intensive care unit should create conditions for active participation of parents in care, it means not only education, but also ensure practical aspects of this active participation, such as free entry to the ward (keys, entrance cards), information by all available means of communication, common meetings with parents at specified intervals, etc.	No		Yes		No	Czech Neonatal Society

15	Finland		4	Yes - Please make your recommendation(s) below.	- add more concrete examples to main text - mention how parental stress may affect their involvement, along with suggested preventative measures to decrease stress - mention structural system-level issues in some countries, such as lack of paid maternity leave, lack of transportation to hospital, etc. that may make it difficult for some parents to be involved during their infants' NICU stay (not sure about EU but the USA are an example) - mention the need to overcome social status and language barriers (in particular for immigrant and refugee parents) when advocating for family centered care	Yes - Please specify below, which evidence should be added (DOIs, references) to the standards and why.	depending on inclusion of suggested items above, respective literature should be added	Yes		No		Individual
16	Australia		4	Yes - Please make your recommendation(s) below.	We must never forget dads and the important role they play. Involving parents, mum and dad, as primary cares for their baby will long term reduce the risk of both maternal and paternal postnatal depression .	No		Yes		No		PRETERM INFANTS' PARENTS' ASSOCIATION IN
17	Germany		5	Yes - Please make your recommendation(s) below.	The component of recording and considering parents' learning and support needs in the care process should be (standardised). Validated needs assessment tools should be used consistently to facilitate the development of psychosocial and educational interventions for parents in the NICU and to match desired parental involvement to the subjective needs of parents. In addressing parental needs, it is crucial to distinguish between how needs are perceived by healthcare professionals and parents themselves. As opposed to healthcare professionals' external evaluation of parental needs, parents' need perception is characterized by subjectivity and agency. Many studies point to a disconnect between parents' actual needs and neonatal nurses' perception thereof. Recent studies suggest that the timely assessment and integration of parents' individual learning needs can lower their levels of experienced stress and distress.(Alves et al. 2016)	Yes - Please specify below, which evidence should be added (DOIs, references) to the standards and why.	E. Alves, M. Severo, M. Amorim, C. Grande, S. Silva, A short form of the neonatal intensive care unit family needs inventory, J Pediatr (Rio J) 92(1) (2016) 73-80.	Yes		No		Charité Universitätsmedizin Berlin
18	Croatia		4	No		No		Yes		Yes - Please enter your conflict(s) of interest.	Cooperation with Nutricia and Thermo Fisher Scientific.	Croatian Society for Neonatology and Neonatal Intensive Medicine