

ANNUAL MEETING
of the Swiss Society of Neonatology
2025

Swiss recommendations for the perinatal care
of extremely low gestational age neonates

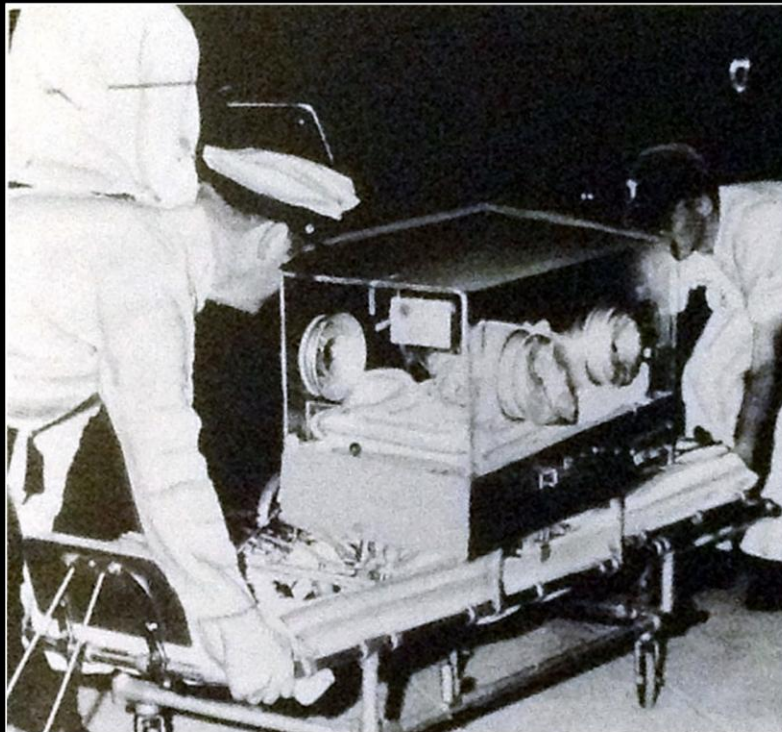
Prof.
Thomas M. Berger
Lucerne



Prof.
Jean-Claude Fauchère
Zurich

Swiss recommendations for the perinatal care of extremely low gestational age neonates

Preliminary Comments: Historical Context

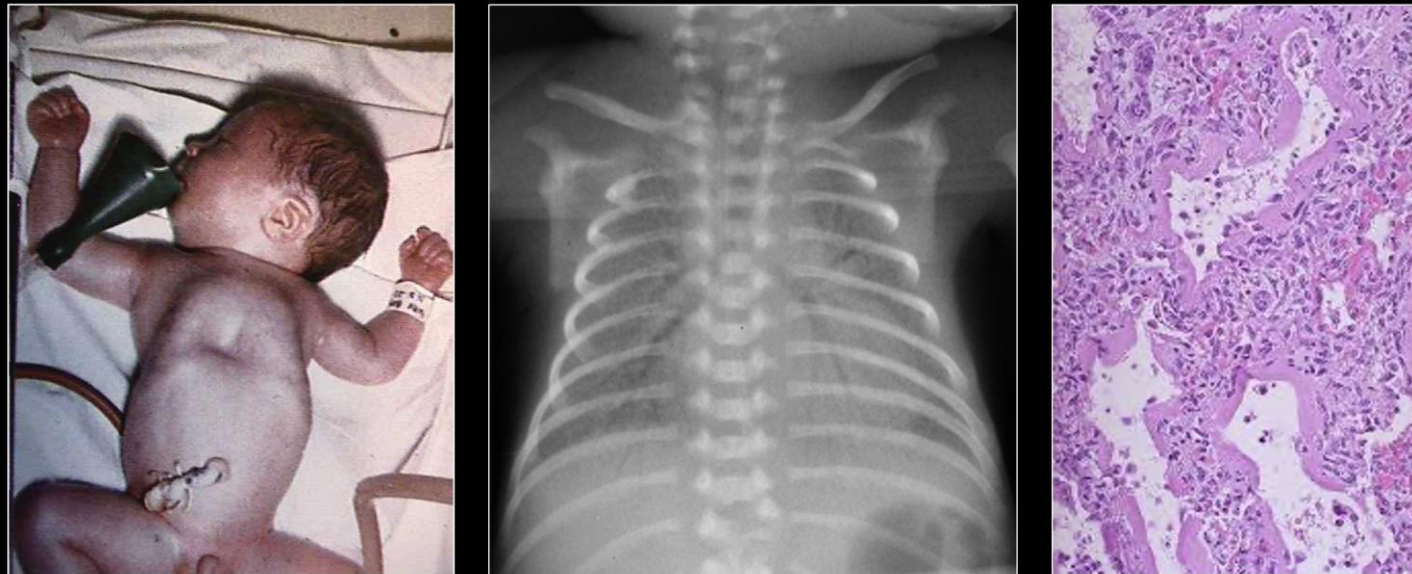


Otis Airforce Base Hospital (1963)

- Caesarean section
- BW 2110 g, GA 34 weeks
- Severe respiratory distress
- Transferred to Boston Children's Hospital

Swiss recommendations for the perinatal care of extremely low gestational age neonates

Preliminary Comments: Historical Context



Boston Children's Hospital
Diagnosis: Hyaline membrane disease
Treatment: hyperbaric oxygen

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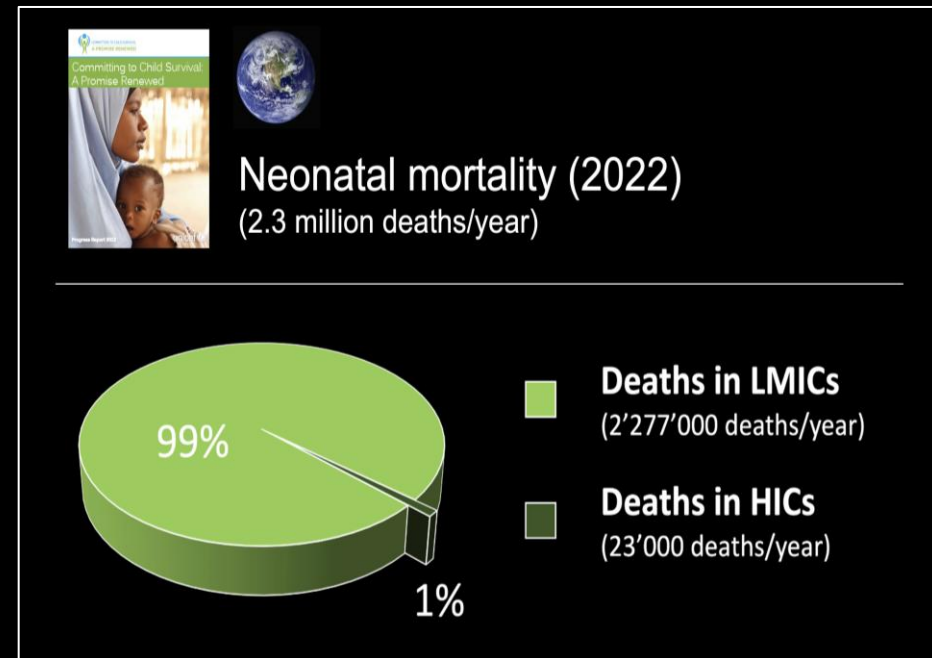
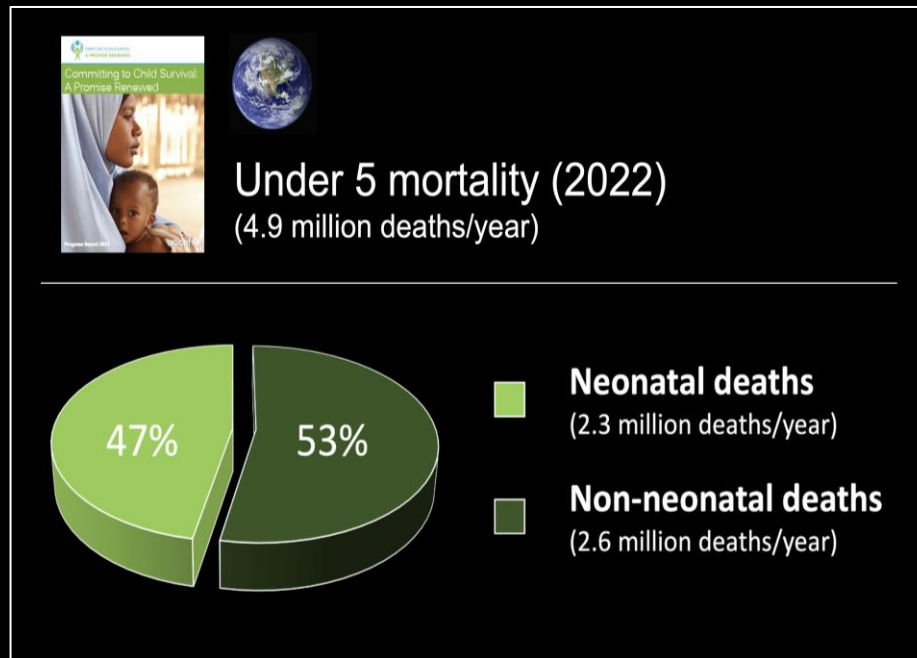
Preliminary Comments: Historical Context



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Swiss recommendations for the perinatal care of extremely low gestational age neonates

Preliminary Comments: Global Perspective



Swiss recommendations for the perinatal care of extremely low gestational age neonates

Preliminary Comments: Global Perspective



Rundu State Hospital (2015)

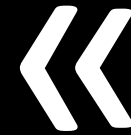
- Vaginal delivery
- BW 1600 g, GA 33 weeks
- Severe respiratory distress

Swiss recommendations for the perinatal care of extremely low gestational age neonates

Preliminary Comments: Global Perspective



Died on DOL 4
No headlines...!



Finally, the authors of these recommendations acknowledge that, globally, the availability of resources and, therefore, the quality of neonatal care continue to differ enormously, leading to wide gaps regarding the definition of what is considered to be the limit of viability. The authors agree that privileged countries should recognize these inequalities and support efforts to diminish the existing gaps.



Swiss recommendations for the perinatal care of extremely low gestational age neonates

Preliminary comments: Limit of Viability?



“How small is too small?” or “How much is too much?”

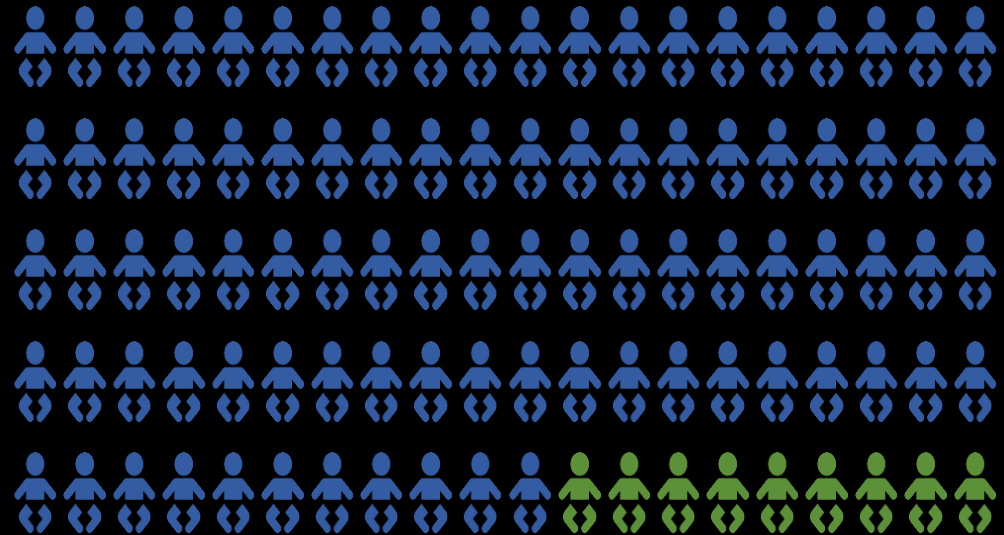
Swiss recommendations for the perinatal care of extremely low gestational age neonates

Preliminary comments: Limit of Viability?



Chances of survival 1%
Risk of death 99%

OR



Chances of survival 10%
Risk of death 90%

Swiss recommendations for the perinatal care of extremely low gestational age neonates

Preliminary comments: Research

Extremely preterm infants: factors in decision-making – NRP 67

Attitudes and values among neonatal health care providers
in Swiss level III NICUs and Swiss society
regarding decision-making in extremely preterm infants

Jean-Claude Fauchère, Manya Hendriks, Sabine Klein, Thomas M. Berger, Ruth Baumann-Hölzle, and Hans Ulrich Bucher



SWISS NATIONAL SCIENCE FOUNDATION

National Research Programme Portrait (NRP 67) 

End of Life

ANNUAL MEETING of the Swiss Society of Neonatology 2025

Swiss recommendations for the perinatal care of extremely low gestational age neonates

Preliminary comments: Previous Versions

Informations / Hinweise

Vol. 13, No. 2, 2002

Empfehlungen zur Betreuung von Frühgeborenen an der Grenze der Lebensfähigkeit (Gestationsalter 22–26 SSW)

Zusammenfassung

Die Betreuung von Früh- und Frönggeborenen an der Grenze der Lebensfähigkeit (22–26 Schwangerschaftswochen) muss multidisziplinär durch ein erfahrenes perinatologisches Team erfolgen. Dabei ist zu berücksichtigen, dass sowohl die eingeschränkte Präzision der Bestimmung des Gestationsalters als auch die biologische Variabilität des Vorgehens im individuellen Fall entscheidend beeinflussen können.

Die zu treffenden Entscheidungen sind komplex und von weitestgehend Bedeutung. Sie werden in einem kontinuierlichen Dialog zwischen allen Beteiligten (Eltern, Pflegepersonal und Eltern) erarbeitet und haben zum Ziel, die Morbidität zu verringern, die im Interesse des Kindes als das besten erachtet werden.

Die Kontexte aktueller, nach Gestationsalter abgeleiteter Mortalitäts- und Morbiditätsstatistiken und die Anwendung anerkannter ethischer Grundsätze geben dabei die Basis für ein verantwortungsvolles Vorgehen. Die Kommunikation zwischen den beteiligten Entscheidungsträgern spielt eine zentrale Rolle.

Aufgrund der aktuell verfügbaren Daten über Mortalität und Langzeitresultate vor sich die Betreuung von Frühgeborenen mit einem Gestationsalter > 24 SSW in der Regel auf Palliativmassnahmen beschränken.

Bei Frühgeborenen mit einem Gestationsalter < 24 SSW muss ein erfahrenes Neonatologie-Team im Gebärhaus entscheiden.

Informationen / Hinweise

Vol. 13, No. 2, 2002

PAEDIATRICA

Downloaded from onlinelibrary.wiley.com on August 29, 2012. Published by group bmg.com

Original article

Trends and centre-to-centre variability in survival rates of very preterm infants (<32 weeks) over a 10-year-period in Switzerland

Thomas M. Berger^{1,2}, Martina A. Steurer², Andreas Wörmser², Philipp Meyer-Schäfer⁴, Mark Adams⁵, for the Swiss Neonatal Network

Abstract

Background: The publication of Swiss guidelines for the care of infants at the limit of viability (22–25 completed weeks) was followed by increased survival rates in the more mature infants (25 completed weeks). At the same time, considerable centre-to-centre (CTC) differences were noted.

Objectives: To examine the trend of survival rates of borderline viable infants over a 10-year period and to further explore CTC-differences.

Design: Population-based, retrospective cohort study.

Patients: 652 preterm infants with a gestational age (GA) < 32 weeks born alive between 1 January 2000 and 31 December 2009.

Main outcome measures: Trends of GA-specific delivery rates and NICU mortality rates and survival rates to hospital discharge were assessed. For CTC comparisons, centre-specific risk-adjusted ORs for survival were calculated in three GA groups: A, 23.0/7 to 25.6/7 weeks (n = 376); B, 25.6/7 to 28.6/7 weeks (n = 1943); and C, 28.6/7 to 31.6/7 weeks (n = 2359).

Results: Survival rates of infants with a GA of 25 completed weeks which had improved from 42% in 2002/2003 to 60% in 2003/2004 remained unchanged at 63% over the next 5 years (2005–2009). Statistically significant CTC differences were persisted and are not restricted to borderline viable infants.

Conclusions: In Switzerland, survival rates of infants born at the limit of viability have remained unchanged over the second half of the current decade. Risk-adjusted CTC outcome variability cannot be explained by differences in baseline demographics or centre trends.

Over the past 20 years, survival rates of infants born at the limit of viability have improved substantially. In some countries, have reached between 55% and 67% and 67% and 81% for preterm infants with a gestational age (GA) of 24 and 25 completed weeks, respectively.^{1–3} At the same time, rates of neonatal mortality are still a major concern, and between 23% and 40% of survivors at 24 completed weeks have been reported to be profoundly impaired (profoundly developmental index (PDI) and/or motor developmental index (MDI) < 50 or IQ < 85; adult assistance is required to move, blindness, deafness). This rate drops below 25% in survivors at 25 completed weeks.^{2–7}

In this present study, we had two aims: first, we wanted to assess whether survival rates at extremely preterm infants have continued to improve in Switzerland. Second, we wanted to

Many national perinatal societies have published recommendations to support ethical decision making in the care of borderline viable infants.^{8–11} The publication of the Swiss recommendations for the care of infants born at the limit of viability (22–25 completed weeks) in the year 2002 was followed by an increase in survival rates in the more mature extremely preterm infants (25 completed weeks) without increasing the rate of short-term complications. At the same time, significant centre-to-centre (CTC) differences in survival rates persisted despite the availability of national guidelines.¹² Because there were no significant differences in baseline population demographics between centres, it is most likely that the observed differences were at least in part due to variations in ethical decision making.¹³ In addition, other factors that have been linked to outcome, such as unit size (i.e. case load) and organisational characteristics (e.g. infant patient status, proportion of outborn infants and staffing) may also have played a role.

In this present study, we had two aims: first, we wanted to assess whether survival rates at extremely preterm infants have continued to improve in Switzerland. Second, we wanted to

What is already known on this topic

- Following the publication of Swiss recommendations for the care of borderline viable infants survival rates of infants at 25 completed weeks improved.
- In Switzerland, considerable centre-to-centre differences in survival rates of borderline viable infants have been noted in earlier studies.

What this study adds

- Since 2004, survival of low born extremely preterm infants with a GA of 24 and 25 completed weeks has not changed significantly.
- In Switzerland, considerable centre-to-centre differences in survival rates continue to persist and extend beyond the borderline viable preterm infant population.

Nationale Empfehlungen sind notwendig, da ethische Entscheidungsfindungen nicht allein

1. Schweizerische Gesellschaft für Neonatologie und Perinatalmedizin (SGNPM)
2. Schweizerische Gesellschaft für Neonatologie und Perinatalmedizin (SGNPM)
3. Schweizerische Gesellschaft für Neonatologie und Perinatalmedizin (SGNPM)
4. Schweizerische Gesellschaft für Neonatologie und Perinatalmedizin (SGNPM)
5. Schweizerische Gesellschaft für Neonatologie und Perinatalmedizin (SGNPM)

PAEDIATRICA

Empfehlungen

PAEDIATRICA Vol. 23, Nr. 1, 2012

Perinatale Betreuung an der Grenze der Lebensfähigkeit zwischen 22 und 26 vollendeten Schwangerschaftswochen

Revision der Schweizer Empfehlungen aus dem Jahre 2002

T. M. Berger^{1,2}, Berner³, S. El Alami⁴, J.-E. Fauchier⁵, L. Hodel⁶, G. Isler⁷, C. Kist⁸, R. Luter⁹, M. Müller¹⁰, R. E. Pfister¹¹, D. Surbek¹², A. C. Trutmann¹³, J. Waser¹⁴, B. Zimmermann¹⁵

Einführung

Die ersten Empfehlungen zur Betreuung von Frühgeborenen an der Grenze der Lebensfähigkeit in der Schweiz wurden im Jahre 2002 veröffentlicht.¹ Als Grundlage dienten damals unter anderem Empfehlungen europäischer^{2–4} und kanadischer Fachgruppen⁵, sowie die relevanten medizinisch-ethischen Richtlinien der Schweizerischen Akademie der Medizinischen Wissenschaften (SAMMW).⁶ Revidierte Empfehlungen aus Nordamerika und Europa^{7,8}, neue Empfehlungen aus weiteren Ländern^{9–11} und neue Daten zu Mortalität und Morbidität^{12–15}, insbesondere auch aus der Schweiz^{16–18}, haben Anlass gegeben, die Empfehlungen für die Schweiz zu überarbeiten.

Nationale Empfehlungen sind notwendig, da ethische Entscheidungsfindungen nicht allein

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5. Schweizerische Gesellschaft für Neonatologie und Perinatalmedizin (SGNPM)
6. Schweizerische Akademie der Medizinischen Wissenschaften (SAMMW)
7. American College of Obstetricians and Gynecologists (ACOG)
8. American College of Obstetricians and Gynecologists (ACOG)
9. American College of Obstetricians and Gynecologists (ACOG)
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14. American College of Obstetricians and Gynecologists (ACOG)
15. American College of Obstetricians and Gynecologists (ACOG)

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Swiss Medical Weekly

The European Journal of Medical Sciences

Review article | Published 18 October 2011, doi:10.4415/SMW.2011.13100

Cite this as: Swiss Med Wkly. 2011;141:e13100.

Perinatal care at the limit of viability between 22 and 26 completed weeks of gestation in Switzerland

2011 Revision of the Swiss recommendations

Thomas M. Berger^{1,2}, Vera Barzel³, Susanna El Alami⁴, Jean-Christophe Fauchier⁵, Yves Hodel⁶, Grotz Isler⁷, Christian Kist⁸, Bas Luter⁹, Markus Müller¹⁰, Riccardo E. Pfister¹¹, Daniel Surbek¹², Anne C. Trutmann¹³, Joseph Waser¹⁴, Roland Zimmermann¹⁵

Summary

Personal care of pregnant women at high risk for preterm delivery and of preterm infants born at the limit of viability (22–26 completed weeks of gestation) requires a multidisciplinary approach by an experienced perinatal team. Limited precision in the determination of fetal gestational age and foetal weight, as well as biological variability may significantly affect the course of action chosen in individual cases.

The decisions that must be taken with the pregnant women and on behalf of the preterm infant at the center are complex and have far-reaching consequences. When counselling pregnant women and their partners, neonatologists and obstetricians should provide them with comprehensive information in a sensitive and supportive way to build a basis of trust. The decision are developed in a continuing dialogue between all parties involved (physicians, midwives, nursing staff and parents) with the principal aim to achieve solutions that are in the infant's and pregnant women's best interests.

Knowledge of current perinatal-specific, neonatal and morbidity rates and how they are modified by prenatally known prognostic factors (maternal foetal weight,

res, exposure or response to antenatal corticosteroids, single or multiple births) as well as the application of accepted ethical principles form the basis for responsible decision-making. Communication between all parties involved plays a central role.

The numbers of the interdisciplinary working group support the fact that the care of preterm infants with a gestational age between 22.0/7 and 24.6/7 weeks should generally be based on palliative care. Obstetric intervention for foetal indications such as Caesarean section delivery are usually not indicated. In selected cases, for example, after 23 weeks of pregnancy have been completed and survival of the neonate is reasonably expected, prenatally known prognostic factors are favourable as well as advanced parents insist on the initiation of life-sustaining therapies, active obstetric interventions for foetal indications and perinatal intensive care of the neonate may be reasonable.

In preterm infants with a gestational age between 24.7/7 and 26.6/7 weeks, it can be difficult to determine whether the benefits of obstetric intervention and neonatal intensive care is justified given the limited chances of success of such therapy. In such cases, the individual conditions

Swiss Medical Weekly - PDF of the online version - www.smw.ch

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2001 (Paediatrics)

Centre-to-centre variability

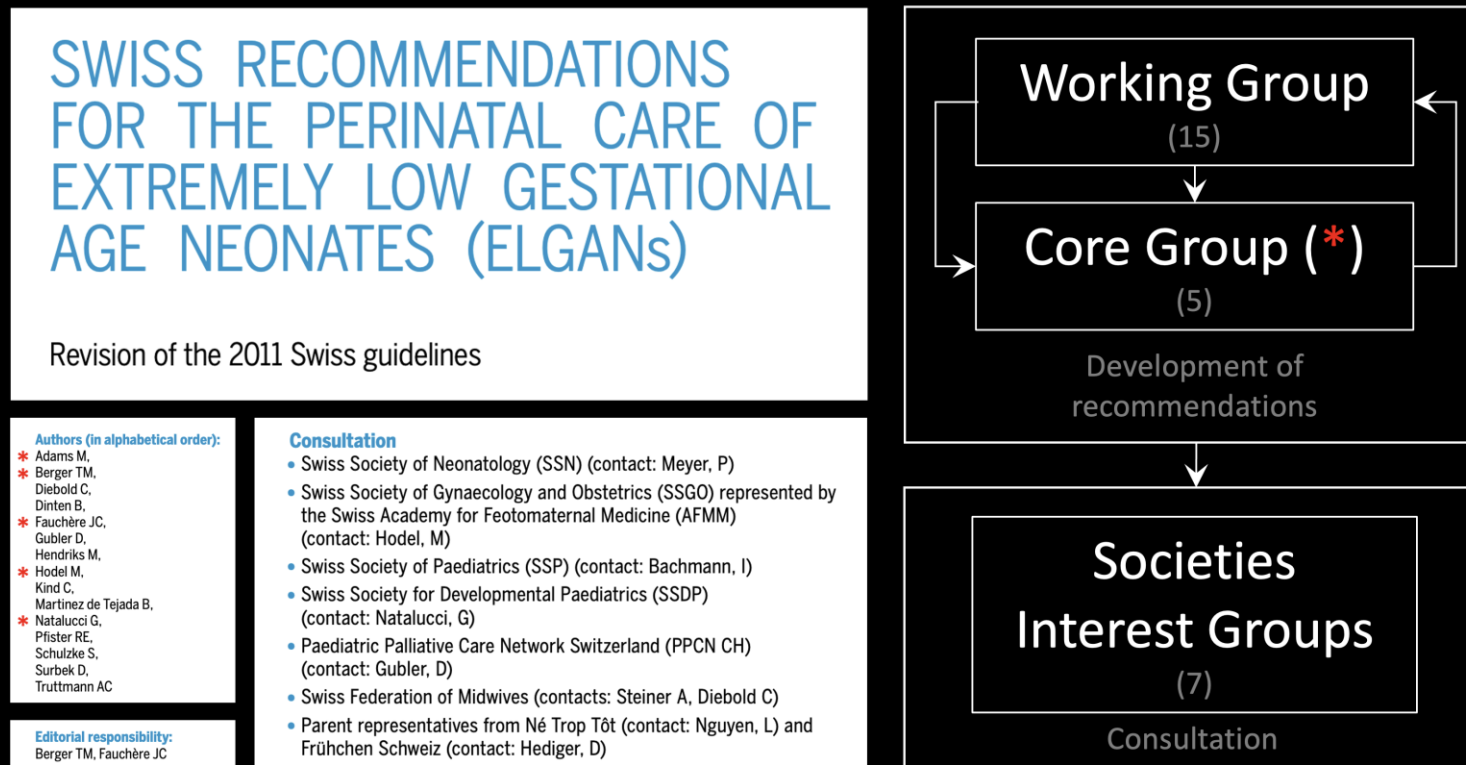
2011 (Paediatrics)

2011 (Swiss Med Wkly)

2025

Swiss recommendations for the perinatal care of extremely low gestational age neonates

Development of New Recommendations



Swiss recommendations for the perinatal care of extremely low gestational age neonates

What is new?

No risk assessment based on GA alone,
except...



« The care of preterm infants with a gestational age below 23 0/7 (as confirmed by first trimester ultrasound scan) should be limited to comfort-focused palliative care. »

Swiss recommendations for the perinatal care of extremely low gestational age neonates

What is new?

Individualised risk assessment by experienced interdisciplinary team

Non-modifiable risk factors

Foetal growth restriction
Foetal sex
Plurality
Foetal malformations
Chorioamnionitis

Modifiable risk factors

Antenatal corticosteroids
MgSO₄
Location of birth
Initial stabilisation

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Swiss recommendations for the perinatal care of extremely low gestational age neonates

Gestational age (GA) example: 24 0/7 weeks		
Factors that affect gestational age (GA) risk		
non-modifiable risk factors	Factors that decrease GA risk	Factors that increase GA risk
	no example: 800 g	yes example: 500 g
	female	male
Plurality	singleton	multiple
modifiable risk factor	Antenatal corticosteroids	yes no
Outcome		
Survival rate (to hospital discharge for babies receiving survival-focused care)		
Survival without severe morbidities ¹ (to hospital discharge for babies receiving survival-focused care)		

estimates are based on prospectively collected data
(2018-2022) from the Swiss Neonatal Network

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Swiss recommendations for the perinatal care of extremely low gestational age neonates

estimates are based on prospectively collected data (2018-2022) from the Swiss Neonatal Network

SwissNeoNet

Gestational age (GA) example: 24 0/7 weeks		
Factors that affect gestational age (GA) risk	Factors that decrease GA risk	Factors that increase GA risk
non-modifiable risk factors		
Foetal growth restriction	no example: 800 g	yes example: 500 g
Foetal sex	female	male
Plurality	singleton	multiple
modifiable risk factor		
Antenatal corticosteroids	yes	no
Outcome		
Survival rate (to hospital discharge for babies receiving survival-focused care)	83% (95% CI, 76–89) 	20% (95% CI, 11–33) 
Survival without severe morbidities ¹ (to hospital discharge for babies receiving survival-focused care)	41% (95% CI, 33–49) 	7% (95% CI, 4–12) 

Swiss recommendations for the perinatal care of extremely low gestational age neonates

What is new? Decision-making process and parental authority

Decision-making process			
Individualised risk assessment by interdisciplinary team considering all factors known to affect prognosis			
Best interest of the child	burden exceeds benefit	balance of burden and benefit unclear	benefit exceeds burden
Management options	survival-focused care clearly not indicated	both survival-focused or comfort-focused palliative care can be considered	survival-focused care clearly indicated
Decision-making with parents	explain situation to parents	shared decision-making: explore, respect and support parental decision	explain situation to parents
Role of parental authority	limited parental authority	full parental authority	limited parental authority
Final management decision	provide comfort-focused palliative care	provide comfort-focused palliative care or survival-focused care	provide survival-focused care

Trajectory A

- Burden clearly exceeds benefit
- Survival-focused care clearly not indicated
- Limited parental authority
- Provide comfort-focused palliative care

Swiss recommendations for the perinatal care of extremely low gestational age neonates

What is new?

Decision-making process and parental authority

Decision-making process			
Individualised risk assessment by interdisciplinary team considering all factors known to affect prognosis			
Best interest of the child	burden exceeds benefit	balance of burden and benefit unclear	benefit exceeds burden
Management options	survival-focused care clearly not indicated	both survival-focused or comfort-focused palliative care can be considered	survival-focused care clearly indicated
Decision-making with parents	explain situation to parents	shared decision-making: explore, respect and support parental decision	explain situation to parents
Role of parental authority	limited parental authority	full parental authority	limited parental authority
Final management decision	provide comfort-focused palliative care	provide comfort-focused palliative care or survival-focused care	provide survival-focused care

Trajectory C

- Benefit clearly exceeds burden
- Survival-focused care clearly indicated
- Limited parental authority
- Provide survival-focused care

Swiss recommendations for the perinatal care of extremely low gestational age neonates

What is new?

Decision-making process and parental authority

Decision-making process			
Individualised risk assessment by interdisciplinary team considering all factors known to affect prognosis			
Best interest of the child	burden exceeds benefit	balance of burden and benefit unclear	benefit exceeds burden
Management options	survival-focused care clearly not indicated	both survival-focused or comfort-focused palliative care can be considered	survival-focused care clearly indicated
Decision-making with parents	explain situation to parents	shared decision-making: explore, respect and support parental decision	explain situation to parents
Role of parental authority	limited parental authority	full parental authority	limited parental authority
Final management decision	provide comfort-focused palliative care	provide comfort-focused palliative care or survival-focused care	provide survival-focused care

Trajectory B

- Balance of burden and benefit unclear
- Both survival-focused or comfort-focused palliative care can be considered
- Full parental authority
- Provide comfort-focused palliative or survival-focused care

Swiss recommendations for the perinatal care of extremely low gestational age neonates

What is new? Shared decision-making (SDM)



- Interdisciplinary approach (*one voice*)
- Senior staff: experience & competence
- Knowledge of current national & local outcome data (Outcome Calculator)
- SDM process requires time and effort
- Active role of parents - bidirectional exchange
- Exploration of parental values & perspectives
- Accept and support parental decision

Swiss recommendations for the perinatal care of extremely low gestational age neonates

What is new? Obstetrical aspects

Comfort-focused palliative care

- No foetal surveillance
- No obstetrical interventions (e.g., Caesarean section) for foetal indications

Survival-focused care

- Consultation at a level III perinatal centre (< 22 0/7 weeks)
- Referral to a level III perinatal centre (\geq 22 0/7 SSW) to optimise modifiable risk factors (e.g., ANC, tocolysis, ABx following PPRM, cervical cerclage, foetal monitoring, mode of delivery, delayed cord clamping)

Swiss recommendations for the perinatal care of extremely low gestational age neonates

What is new? Neonatal aspects

Comfort-focused palliative care

- Inform parents that infant might show signs of life
- Do not separate infant from parents
- Minimise potential suffering (i.e., provide warmth, skin-to-skin contact, swaddling, opiates if needed)
- Also applies to the care of infants following redirection of care

Survival-focused care

- Delivery must be attended by an experienced neonatology team
- No *a priori* exclusion of interventions considered to be effective in more mature infants (e.g., lung protective respiratory support, vascular access, continuous monitoring, cardiovascular support, parenteral nutrition)

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What is new?
Appendix I: Recent outcome data

Gestational age (weeks)	Switzerland 2019-2023 SNN ¹⁰ (N = 710)	USA 2013-2018 NICHD ⁶⁷ (N = 4635)	Japan 2008-2012 NDNJ ⁶⁹ (N = 1839)	Sweden 2004-2007 Express ⁶⁸ (N = 501)	France 2011 EPIPAGE 2 ⁶⁶ (N = 641)	Norway 2013-2014 NEPS2 ⁷¹ (N = 191)	UK 2006 EPIcure 2 ⁷⁰ (N = 1454)	Netherlands 2018-2020 EPI-DAF ⁷² (N = 568)
Denominator	All liveborn infants							
22 0/7 - 22 6/7	100%	81%	54%	90%	100%	82%	98%	-
23 0/7 - 23 6/7	73%	51%	27%	48%	99%	71%	81%	-
24 0/7 - 24 6/7	37%	30%	15%	33%	69%	44%	60%	58%
25 0/7 - 25 6/7	18%	21%	-	19%	41%	16%	34%	31%

All liveborn infants
23 0/7 - 23 6/7 weeks (CH): MR 73%

Gestational age (weeks)	Switzerland 2019-2023 SNN ¹⁰ (N = 533)	USA 2013-2018 NICHD ⁶⁷ (N = 4117)	Japan 2008-2012 NDNJ ⁶⁹ (N = 1796)	Sweden 2004-2007 Express ⁶⁸ (N = 432)	France 2011 EPIPAGE 2 ⁶⁶ (N = 405)	Norway 2013-2014 NEPS2 ⁷¹ (N = 168)	UK 2006 EPIcure 2 ⁷⁰ (N = 1265)	Netherlands 2018-2020 EPI-DAF ⁷² (N = 485)
Denominator	Infants receiving survival-focused care				Infants admitted to a neonatal intensive care unit			
22 0/7 - 22 6/7	100%	70%	49%	74%	100%	40%	84%	-
23 0/7 - 23 6/7	42%	44%	25%	35%	86%	65%	70%	-
24 0/7 - 24 6/7	31%	29%	15%	27%	49%	42%	53%	46%
25 0/7 - 25 6/7	17%	20%	-	17%	36%	14%	31%	25%

Infants receiving survival-focused care
23 0/7 - 23 6/7 weeks (CH): MR 42%

Importance of denominator used

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What is new?

Appendix I: Recent outcome data

Gestational age 23 0/7 - 23 6/7 weeks	Mortality rates	Survival with severe ^a impairment	Survival with moderate ^b impairment	Survival without severe or moderate impairment
Denominator	All liveborn infants	Survivors at follow-up		
SNN ¹⁰	90%	29%	21%	50%
EXPRESS ⁹⁴	50%	22%	35%	43%
EIPAGE 2 ⁹³	99%	-	-	-

Gestational age 24 0/7 - 24 6/7 weeks	Mortality rates	Survival with severe ^a impairment	Survival with moderate ^b impairment	Survival without severe or moderate impairment
Denominator	All liveborn infants	Survivors at follow-up		
SNN ¹⁰	50%	11%	26%	63%
EXPRESS ⁹⁴	35%	19%	21%	60%
EIPAGE 2 ⁹³	69%	34%		66%

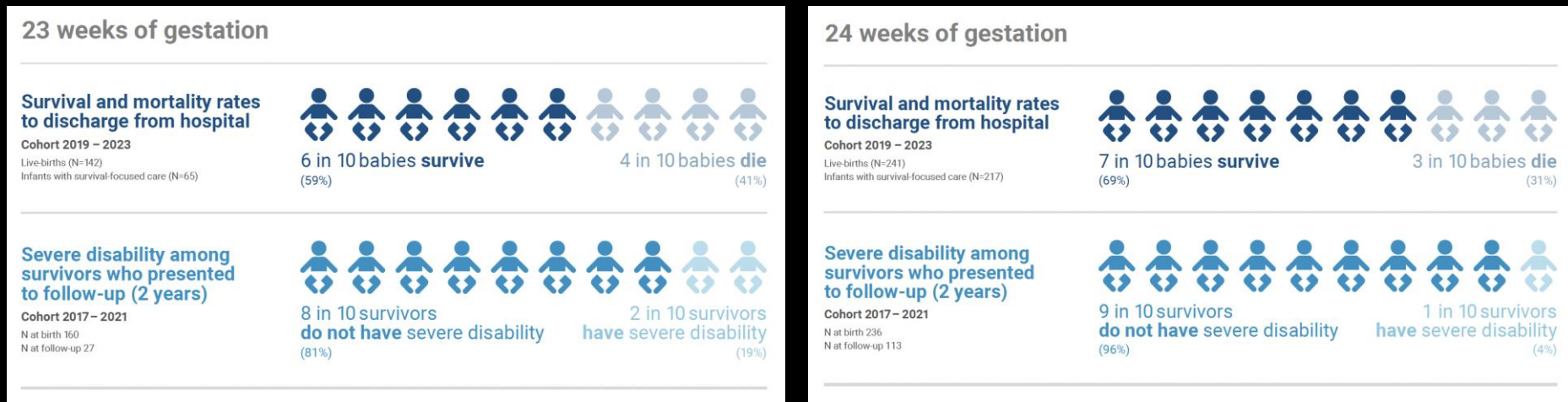
Mortality and impairment rates
Switzerland (2013-2017) vs Sweden & France

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What is new?

Appendix II: Visual aids

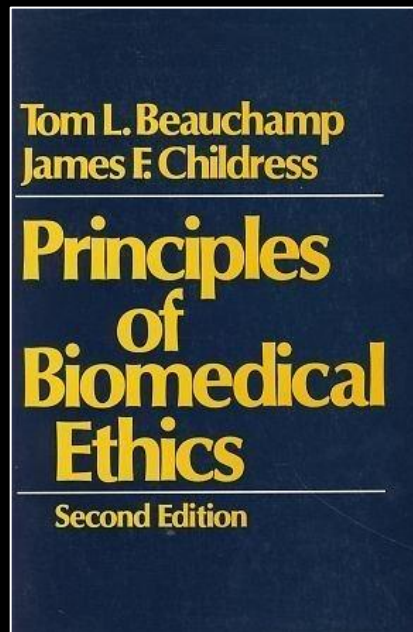


Avoid message framing
(mention both chances of survival and risk of mortality)

Swiss recommendations for the perinatal care of extremely low gestational age neonates

What is new?

Appendix III: Ethical decision-making and SDM



Patient autonomy

- parental authority

Beneficence

Nonmaleficence

Justice

- global view

ANNUAL MEETING

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2025

Swiss recommendations for the perinatal care
of extremely low gestational age neonates

THANK
YOU
FOR YOUR
ATTENTION!



ANY
QUESTIONS?