UPDATED RECOMMENDATIONS FOR ROUTINE NEURODEVELOPMENTAL FOLLOW-UP ASSESSMENTS OF HIGH-RISK NEWBORNS IN SWITZERLAND.

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ABBREVIATIONS

BSID-III: Bayley Scales of Infant Development, 3rd edition, **CHD:** Congenital Heart Disease, **CP:** cerebral palsy, **EP:** extremely preterm, **FU:** Follow-up, **GA:** gestational age, **HIE:** hypoxic-ischemic encephalopathy, **K-ABC II:** Kaufman Assessment Battery for Children, 2nd edition, **ND:** neurodevelopment, **SES:** socioeconomic status, Swiss **ORCHID:** Swiss Outcome Registry for CHIldren with severe congenital heart Disease, **SwissNeoNet:** Swiss Neonatal Network & Follow-Up Group, **VP:** very preterm, **ZNA-2:** Zurich Neuromotor Assessment, 2nd Edition.

Abstract:

Recommendations for the neurodevelopmental follow-up assessments of high-risk newborns in Switzerland were first published in 2014. Since that time, clinical advancements and new scientific evidence have necessitated an adaption of the at-risk groups, and the clinical proceedings. Meanwhile, high-risk newborns in the context of these guidelines are children who were born extremely preterm (before 28 weeks gestational age), with a congenital heart defect (CHD), requiring open-heart surgery in the first year of life, or who developed a moderate to severe hypoxic ischemic encephalopathy (cooled or not cooled) during the first hours of life. This paper presents an update of the 2014 recommendations for routine neurodevelopmental follow-up assessments of high-risk newborns in Switzerland. It is endorsed by SwissPediatrics, the Swiss Society of Neonatology, and the Swiss Society of Developmental Pediatrics.

Introduction

Background

The benefits of standardized developmental surveillance and screening of high-risk newborns are to ensure early detection of developmental delay, to provide parental counselling, and to guarantee quality control and monitoring with the aim to improve neonatal care[1,2]. In Switzerland, family pediatricians and general practitioners in private practice are the main providers of developmental and preventive health screening for the general population of children. The recommendations of the Swiss Society of Pediatrics regarding screening are comparable to the guidelines of the American Academy of Pediatrics[3]. International guidelines also emphasize the need for evidence-based programs of developmental surveillance for children at higher risk of disability, including children born prematurely[4], with congenital heart disease (CHD)[5] or after suffering from hypoxic-ischemic encephalopathy (HIE)[6]. With increased survival rates for all three patient groups associated with excellent neonatal, intensive care and surgical technique, the focus has shifted towards improving outcome and reducing long-term morbidity. Therefore, it is mandatory for tertiary centers in most developed countries to provide a neurodevelopmental follow-up (FU) program for their at-risk patients[7,8].

The national registry of high-risk newborns and its follow-up program (Swiss Neonatal Network & Follow-Up Group [SwissNeoNet]) was started in the year 2000, and a first version of the Swiss guidelines was published in 2014[9]. This is thus an update of these recommendations. Among infants with high neurodevelopmental risk, the three most prevalent groups are included in this national registry and followed-up according to standardized protocols. Nevertheless, children at risk not included in the registers are also offered developmental follow-up.

Target populations

Children born preterm

In Switzerland, 6,3 % of babies were born preterm (gestational age [GA] < 37 weeks) in 2022, with subgroups of 0,6 % very preterm (VP, $28^{0/7}$–$31^{6/7}$ weeks), and 0,4 % extremely preterm (EP, 22–$27^{6/7}$ weeks) born children, which is in the lower range of available international data[10]. Over the last decades, mortality and severe morbidity of children born EP has dramatically declined, but the rate of neurodevelopmental sequelae has remained high[11]. Specific developmental problems, such as motor impairments, visuospatial problems, cognitive impairments, attention deficit hyperactivity disorder, or autism spectrum disorder have been reported at much higher prevalences than in the general population, ranging from 15 % (developmental language disorder) to 50 % (executive function deficits)[12–14].

Among children born EP, around 20 % survive without any neurodevelopmental impairment[15]. In line with international studies, a Swiss cohort of children born in 2006 before 30 weeks of gestation had a mortality rate of 30 % (24 % were EP, and 6 % VP). At the age of five to six years, 20 % of the survivors had a mild cognitive impairment (defined as IQ 70–84) and 3,5 % a moderate to severe cognitive impairment (defined as IQ < 69)[16]. A characteristic cognitive and behavioral profile seems to emerge in children born preterm, even without major brain lesions, with 55 % of all children having difficulties in multiple domains. Recent publications show that in a population of VP children at the age of five years old, 45 % reported no difficulties, the remainder had difficulties in multiple domains, such as cognition, language, motor coordination, executive functions, attention, social adaptation and behavior, isolated or combined[17].

Children with hypoxic ischemic encephalopathy

Perinatal asphyxia due to maternal or fetal causes may lead to a lack of cerebral oxygenation and to hypoperfusion, with the clinical picture of hypoxic-ischemic encephalopathy (HIE) in the newborn[18]. HIE affects around 1 to 3 of 1000 live births in high-income countries and is a major cause of neonatal death (9 % of deaths before 5 years of age) and adverse neurodevelopmental outcome, such as dyskinetic CP, epilepsy, or hearing impairments[19,20]. In middle- and low-income countries, the incidence is even higher. Since the introduction of therapeutic hypothermia as a neuroprotective treatment, the rate of death and severe disability after HIE has dramatically declined[19,21,22]. Nevertheless, despite therapeutic hypothermia the survivors present with more neurodevelopmental impairments at school-age than healthy controls, which may affect the development of intelligence, language, memory, motor skills and behavior[23,24]. Children with mild HIE, who are not treated with therapeutic hypothermia, may also have a higher rate of neurodevelopmental impairments compared to healthy controls[20].

Current therapeutic trials of potential neuroprotective drugs have failed to show benefits (e.g., erythropoietin, allopurinol, cannabinoids)[25,26]. Therefore, more research on additional neuroprotective interventions is needed and ongoing.

Children with Congenital Heart Disease

The number of children and adults growing up with CHD in Switzerland is increasing steadily[27]. The annual incidence ranges from 0,8 % to 1,2 %[28]. After more than three decades of medical advances with improved cardiac, surgical, and intensive care treatment of children with severe CHD, the overall survival rate has improved significantly, and more than 90 % of patients treated for CHD survive into adulthood. Nevertheless, children with severe CHD are at risk for neurodevelopmental impairments[29], which in turn affects social integration and participation[30]. A consistent pattern of global developmental impairments has been described in the first two to three years, with motor delays and neuromotor abnormalities being more prominent than intellectual and language impairments[31–33]. However, school-aged children,

adolescents and adults with CHD also show long-term neurocognitive impairments[29], affecting all developmental domains, in particular executive functions[34] which lead to school and educational difficulties, and can impact professional careers and quality of life. In response to the increased risk for neurodevelopmental impairment in patients with CHD, the Cardiac Neurodevelopmental Outcome Collaborative (CNOC) has published recommendations for the neurodevelopmental evaluation of this population[5,35,36]. For Switzerland, corresponding recommendations and the national «Outcome Registry for Children with severe congenital heart Disease» (ORCHID) exist since 2019[37].

With these different risk factors, often the early impairments persist into later childhood, adolescence and beyond and new difficulties emerge as academic and psychosocial demands increase, even if early development has been within the normal range («growing into deficit»)[31,38–40]. Deficits often tend to be mild to moderate but likely lead to cumulative functional impairments resulting in increased use of special education and therapeutic services[11,39,41]. Although a «typical» picture of overall cognitive and behavioral phenotypes has been described in all three at-risk groups, the individual neurocognitive long-term outcome varies considerably between children[42–45].

Benefits of early detection of children and families in need of support

Early interventions

There is extensive literature on the importance of interventions for infants with developmental risks, or impairments in early childhood[46–49]. Children diagnosed with developmental delay have better health and educational outcomes if detected and treated early in life[50,51], parental stress can be significantly reduced[52,53], and intervening early even offers economic benefits for society[18,54,55]. Therefore, optimal care for patients with developmental delay aims at initiating support early in live[56], which can only be achieved by screening children at risk and early detecting affected children[57]. Later, also other forms of support (i.e., integration aides, social work, etc.), therapies (e.g., occupational therapy, psychotherapy, etc.), or special schooling can be needed.

Parental counseling by health care professionals

Early detection of children's challenges is crucial in pediatric counseling because it allows for timely intervention and support, minimizing the potential long-term impact on a child's well-being. Identifying developmental difficulties early enables parents to access resources, therapeutic interventions, and guidance, fostering healthier development and stronger parent-child relationships. Proactive engagement at an early stage also enhances the likelihood of successful outcomes in addressing and managing potential concerns. Furthermore, parents highly appreciate being counselled on their children's development and possible measures of support[46,58].

Improvement and surveillance of quality of care

Beside early detection of children with developmental delay, standardized data collection in a register of at-risk children allows national and international comparisons of treatment strategies or outcome and is therefore an important tool for quality assurance and benchmarking. On this basis, the SwissNeoNet has also helped to improve neonatal care[59,60]. Furthermore, political or societal decisions should be well founded, and based on high quality data.

Development of new therapeutic interventions

New therapeutic interventions benefitting high-risk newborns are usually developed using randomized clinical trials. For safety reasons, these trials require long-term outcome results to ensure that the tested interventions, often new drugs, are more beneficial than harmful[61]. Postnatal systemic steroids to reduce bronchopulmonary dysplasia in very preterm infants have for instance been associated with an increase in cerebral palsy which could have been avoided with more rigorous long-term observation of the trials[62]. However, because of the low economic importance of neonatal research, neonatology is largely dependent on sponsor-initiated research with limited funds. A follow-up program existing for clinical reasons and an existing data registry thus also foster developing safer new inventions for children at high risk for adverse outcome.

Purpose of the follow-up examinations of high-risk newborns in Switzerland

The purpose of follow-up assessments within the Swiss Neonatal Network & Follow-Up Group (SwissNeoNet*) therefore is to provide early detection of neurodevelopmental impairments in high-risk children using standardized assessment tools[63,64]. This allows for early interventions and facilitates parental counseling. The SwissNeoNet and Follow-up group published the aims of this network in 2014[9]. In the meantime, inclusion criteria and assessments methods have changed, justifying this update of national guidelines. It summarizes the current standards for follow-up assessments, which were established in Switzerland in 2006, and since are adapted as needed in the biannual network meetings of the SwissNeoNet. They document a consensus on best ways to conduct follow-up assessments on high-risk infants in Switzerland. However, the standards also respect regional differences and describe purpose, location, content, follow-up ages, and recruiting strategies. The network monitors the most important outcome variables, relates them to neonatal care, and compares them between units, thus enabling the detection of potential areas of quality improvement[63,64].

Methods

Aims and purpose

On the initiative of the Swiss centers providing level-III neonatal care and developmental surveillance, the SwissNeoNet was founded in 1996 to systematically report mortality, morbidity, and neurode-

*https://swissneonet.ch

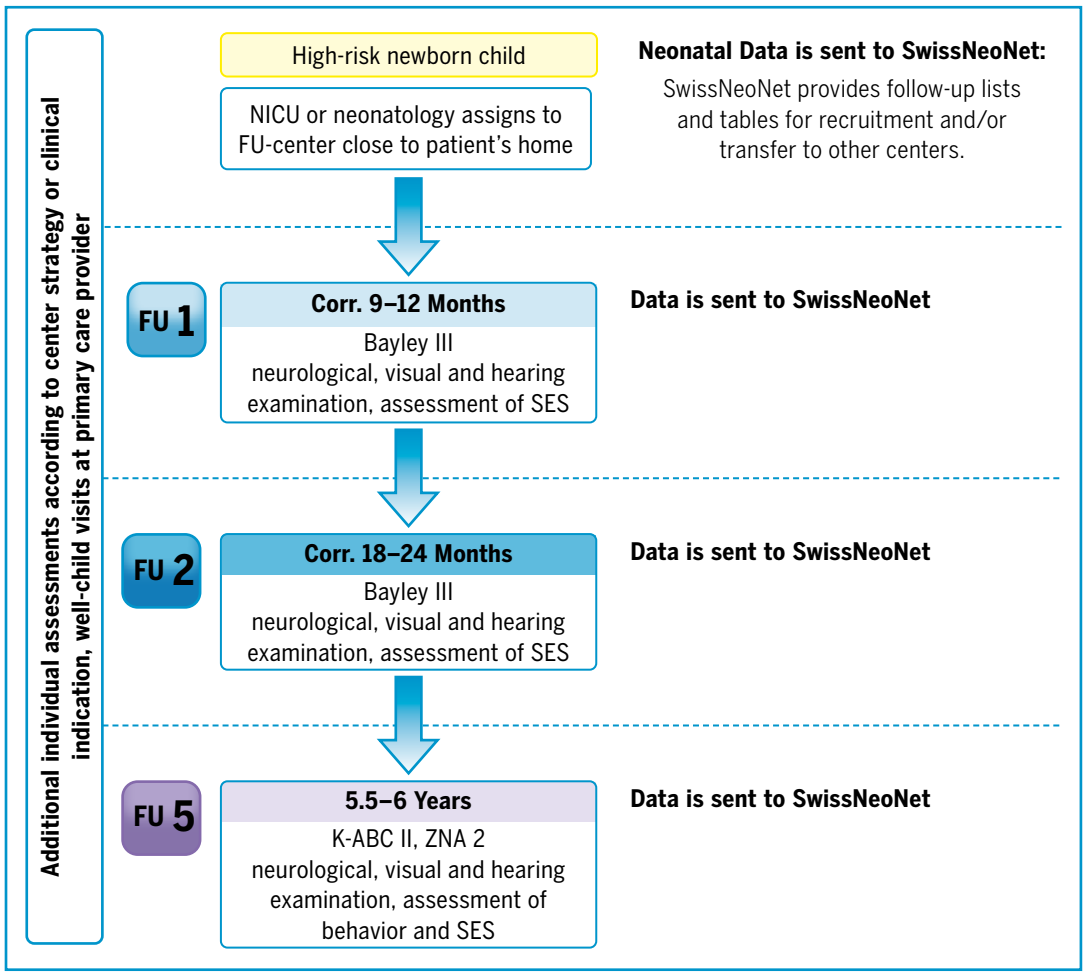

Figure 1: *Standard FU-schedule, and data collection for SwissNeoNet*
Schematic illustration of routine follow-up appointments. High-risk newborn child: Preterm birth < 28 weeks' gestation, hypoxic ischemic encephalopathy (cooled or not cooled) with Sarnat score >1 or Thompson score >=7, born with severe congenital heart disease requiring bypass surgery within the first six weeks of life. NICU: Neonatal Intensive Care Unit, FU: Follow-Up, SwissNeonet: Swiss Neonatal Network & Follow-Up Group, Bayley III: Bayley Scales of Infant Development, 3rd edition, SES: socioeconomic status, K-ABC II: Kaufman Assessment Battery for Children, 2nd edition, ZNA 2: Zurich Neuromotor Assessment, 2nd edition.

velopmental outcome of high-risk newborns in a national register. The aim was to provide standardized, continuous follow-up assessments of high-risk newborns across Switzerland, and enter the data into a register, which allowed for comparisons between centers, but also with internationally available outcome data to improve the quality and efficiency of medical care for specific high-risk newborns[63,64]. The scope of the FU program has since been extended to children born with HIE in 2011[64], and CHD in 2019[37]. By registering neurodevelopmental outcome within SwissNeoNet, epidemiological data is gathered which allow for nationwide, population-based information on outcome in all three at-risk populations. The history, purpose, structure and achievements of SwissNeoNet have just recently been described in a review by Adams et al[64]. The network has a threefold responsibility: clinical (i.e., to offer early detection and treatment), monitoring (outcomes and treatments), and quality control in all three at-risk populations. In addition, it fosters collaborative research on a national and international level. SwissNeoNet thus maintains and improves the quality and safety of medical care for these high-risk newborn infants. Furthermore, a broad body of literature has been published based on the joint data collection, proving its clinical value[16,42,58,65–73].

Registry design and inclusion criteria

The data collected by the members of the network are entered into a state-of-the-art population-based secure online registry for high-risk newborns in Switzerland. It provides the basis for both research and quality control. The registry includes clinical, surgical, and neurodevelopmental variables, and has been presented to the cantonal Ethics committees (Neonet&HIE: PB_2016-02299; ORCHID: Req-2019-00089). The registry holds continuous standardized population-based data for extremely preterm born infants since 2000 (initially also including very preterm born infants), for term infants with HIE since 2011, and for CHD patients since 2019. SwissNeoNet col-

lects routine neurodevelopmental FU for all children that meet the following inclusion criteria:

- Preterm birth < 28 weeks' gestation
- Hypoxic ischemic encephalopathy with a Sarnat score > 1 or Thompson score >=7 (cooled or not cooled)
- Born with severe congenital heart disease requiring bypass surgery or hypoplastic left heart syndrome with hybrid approach within the first six weeks of life.

At two and five to six years of age, follow-up examinations are performed uniformly throughout Switzerland using commonly agreed assessment batteries to ensure comparability of results. Additional follow-up examinations are performed at intervals determined by each center based on the clinical course or individual indication. Further, some centers extend the described FU routine to any hypoxic ischemic encephalopathy (cooled or not cooled), or all newborns < 32 weeks GA, and additionally see them for a three-months visit. Also, some centers offer FU visits according to the above-described schedule to all CHD children with bypass surgery within the first year of life. However, in the CHD population, central collection and transfer of FU data is restricted to children with surgery in the first six weeks of life. It is important to note, that independent of these FU examinations, regular well-child visits are performed by pediatricians in private practice, as recommended by national guidelines.

Neurodevelopmental assessment tools:

For the two milestone ages of two and five to six years old, all FU centers agreed on standardized, internationally used assessment tools with normative values and allow for nationwide and international comparisons. All FU visits include a medical history, and updates of current or terminated therapies. Additionally, there is an assessment of growth parameters, a physical and a neurological examination including hearing and vision. The age is corrected for prematurity until the completion of the two-year examination.

At 18 to 24 months old (maximum age range 15 to 29 months, corrected for prematurity if necessary), the standardized assessment tool is:

- Bayley Scales of Infant and Toddler Development, 3rd edition (BSID-III), assessing cognitive, language, motor development[74]. The changeover to 4th edition (BSID IV) will be completed as soon as translations are available in the national languages.
- When cerebral palsy is diagnosed, it is graded using the Gross Motor Function Classification System (GFMCS)[75]

At 5 to 6 years (maximum age range 4,5 to 6,5 years)

- Kaufmann Assessment Battery for children, 2nd version (K ABC-II)[76] (or, as a substitute the Wechsler Preschool and Primary Scale of Intelligence – Fourth Edition (WPPSI-IV)[77]) to assess intelligence
- Zurich Neuromotor Assessment, 2nd edition (ZNA-II) assessing fine and gross motor function[78]
- Strengths and Difficulties Questionnaire (SDQ)[79], optional
- When cerebral palsy is diagnosed, it is graded using the Gross Motor Function Classification System (GFMCS)[75]

In addition, the socioeconomic status (SES), the strongest predictor of ND outcome, is assessed for all infants and children at each FU time point[80] and is defined by parental education and occupation.

Structure of the FU network

SwissNeoNet consists of all tertiary care centers that combine neonatal with developmental- and/or neuropediatric units[63], centers performing cardiopulmonary bypass surgery in infants[37], and additional regional follow-up centers, to ensure the highest possible follow-up rates across the nationwide follow-up network *(see Table 1)*.

Within this network, level-three neonatology units and cardiac centers collect neonatal and surgery-related baseline characteristics, and 16 FU centers are responsible for the data collection of the neurodevelopmental outcome assessments. Neurodevelopmental FU centers ensure quality of care, e.g., by participating in the regular FU-group meetings *(see Box 1)*.

Box 1: Standards for FU-centers

- Department of developmental pediatrics or child neurology including affiliated private practices
- Represented in the regular FU-group meetings
- Standard FU assessment battery regularly performed, quality control measures
- Responsible for FU for a defined (i.e., regional) subgroup of the cohort

Results

Since we started data collection, the average number of eligable children per year was 176 EP children, 72 children with HIE, and 50 with severe CHD requiring heart surgery. In total, so far (by the end of 2023) 4039 EP children have been registered, 931 children with HIE, and 198 children with severe CHD requiring heart surgery (data collection started in 2019). A follow-up rate of more than 80 % at the two-year controls could be achieved in almost all cohorts. In

contrast, the rate for five-year FU is significantly lower, ranging between 60 and 78 % for EP born children, and between 40 and 67 % for children with HIE. For children with severe CHD, data collection started in 2019, hence, information on the five-year FU is not available yet.

The data collected within SwissNeoNet allows for national comparisons between the different Swiss units to improve outcome and process measurements of the different populations at risk[65–67] as well as for international collaborations and comparisons for different aspects of outcome measures and quality assurance[68–70]. Among the numerous studies based on data of SwissNeoNet, Grass et al.[71] demonstrated an association between short-term neurological improvement and neurodevelopmental outcome at 18 to 24 months after therapeutic hypothermia, while El Faleh and colleagues[72] developed and validated a risk score for bronchopulmonary dysplasia. Pittet-Metrailler et al.[16] reported the outcome of a cohort of very preterm children at early school age and showed that they are at increased risk of cognitive impairment and that a close monitoring of their further development even after school entry is necessary. In the context of the COVID-19 pandemic Adams et al.[73] found no reduced preterm birth rate but a higher odds of respiratory distress syndrome and a possibly higher provision of continuous positive airway pressure (CPAP) within the first nine months of the pandemic. Furthermore, the level of therapeutic support can be evaluated, and compared. In a recent dissertation thesis evaluating the parents' experiences with the FU program, parents of premature born children expressed high levels of satisfaction with the FU consultations[58]. However, a comparative study based on the registry showed, that children with CHD receive fewer therapies despite a comparable burden of neurodevelopmental impairments[42].

Ongoing projects include retrospective observational studies of the epidemiology and predictors of morbidity and mortality of NEC, or incidence and severity of cerebral palsy after intraventricular hemorrhage and periventricular hemorrhagic infarction in preterm infants. Also, investigating possibilities of early clinical prediction of complications such

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Table 1: *FU-centers*
*Developmental pediatric and neuropediatric units in Switzerland performing neurodevelopmental follow-up of high-risk newborns. Centers that combine neonatal with developmental- and/or neuropediatric units are indicated with an *. Contact information: see www.swissneonet.ch/de/fu_centers*

as bronchopulmonary dysplasia in extremely preterm infants, or of adverse outcome in children with CHD are currently underway.

Discussion

Developmental monitoring, screening, and assessment of children in Switzerland follows a standardized yet individualized approach tailored to recognize risk factors for developmental impairments. While routine developmental surveillance is mainly carried out by primary care providers, standardized FU of at-risk populations up to the age of five years is mandatory for centers providing highly specialized care. Over time, new cohorts, such as HIE and CHD patients, could be successfully added. In 2023, the three populations comprised 214 EP infants, 74 infants with HIE and 55 infants with CHD, who were followed in 16 centers in Switzerland. The de-identified data from these populations are recorded in a national registry, allowing monitoring of the quality of care, comparisons between centers, but also with international consortia, which confirmed that Switzerland has a high international standard of neonatal care[69,81]. The applicable recommendations are continuously adapted to current developments and international guidelines (e.g., the European guidelines for the FU of CHD children, currently in preparation) by the group of dedicated FU centers to maintain the existing high standards and ensure the quality of monitoring.

Challenges of specialized FU, ongoing projects and outlook

As most children in Switzerland receive standard developmental monitoring, families and sometimes pediatricians need to be convinced of the benefits of this additional FU program. However, good FU rates (>80 %) are essential for reliable data, quality control, research and intervention protocols. Each center is therefore committed to providing the best quality of care to the population, despite financial pressures and increasing social and developmental difficulties in the population. In addition, a national specialized follow-up program requires measures to guarantee the quality of care and training in common tools, all of which are discussed at mandatory twice-yearly meetings. This effort stands in contrast to the available personnel resources at the participating centers, which represent a challenge for a comprehensive FU program, which is one of the reasons for lowering the cut-off for the FU of former premature babies to 28 weeks' gestation.

Children at high risk of developmental and learning difficulties are offered standardized FU up to the age of five, and yet many learning or social difficulties or behavioral and mental health disorders become apparent later, well into adolescence, when the lack of standardized follow-up means that patients are not offered timely treatment. «Growing into deficit» has been described as a phenomenon observed in all three populations, particularly for executive function problems, mental health problems or social communication problems with increased demands on these abilities. We therefore propose a collaborative effort to implement a nationwide screening strategy at ten to twelve years of age using validated questionnaires, or to extend neurodevelopmental assessment as proposed by Ilardi et al. for children with CHD even into adolescence[5]: they recommend that primary care providers monitor further developmental progress beyond the FU schedule. Referrals to neuropsychologists or developmental pediatricians should be made whenever suspicion is raised (e.g., concerns from parents or teachers).

Further developments of the network might turn to including other at-risk groups such as children with gastrointestinal malformations requiring surgery within the neonatal period, or children exposed to maternal drug abuse during pregnancy. In addition, the inclusion of parents/caregivers and patients has become the standard in clinical research (patient-oriented research)[82]. This will certainly become increasingly important when deciding on the questions that should be addressed using the registry data from a parental perspective, which relevant outcomes matter to them, or which information material should be made available to parents.

Conclusions

Developmental monitoring, screening, and assessment of children in Switzerland follows a standardized yet individualized approach tailored to recognize risk factors for developmental impairments. A group of dedicated FU centers ensures standardized aftercare following defined procedures and schedules, which are jointly agreed on. Consecutively, high quality outcome data are recorded in a national registry, allowing for benchmarking and deriving up-to date scientific evidence on risk factors, treatments, and neurodevelopmental outcome. Therefore, these recommendations are endorsed by SwissPediatrics, the Swiss Society of Neonatology, and the Swiss Society of Developmental Pediatrics.

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References

1) Miller TA, Sadhwani A, Sanz J, Sood E, Ilardi D, Newburger JW, et al. Variations in practice in cardiac neurodevelopmental follow-up programs. Cardiol Young. 2020 Nov;30(11):1603–8.
2) Spittle AJ, Anderson PJ, Tapawan SJ, Doyle LW, Cheong JLY. Early developmental screening and intervention for high-risk neonates - From research to clinical benefits. Semin Fetal Neonatal Med. 2021 Jun;26(3):101203.
3) Lipkin PH, Macias MM. Promoting Optimal Development: Identifying Infants and Young Children With Developmental Disorders Through Developmental Surveillance and Screening. Pediatrics. 2020 Jan;145(1):e20193449.
4) Bilsteen JF, Alenius S, Bråthen M, Børch K, Ekstrøm CT, Kajantie E, et al. Gestational Age, Parent Education, and Education in Adulthood. Pediatrics. 2022 Jan 1;149(1):e2021051959.
5) Ilardi D, Sanz JH, Cassidy AR, Sananes R, Rollins CK, Shade CU, et al. Neurodevelopmental evaluation for school-age children with congenital heart disease: recommendations from the cardiac neurodevelopmental outcome collaborative. Cardiol Young. 2020 Nov;30(11):1623–36.
6) Molloy EJ, El-Dib M, Juul SE, Benders M, Gonzalez F, Bearer C, et al. Neuroprotective therapies in the NICU in term infants: present and future. Pediatr Res. 2023 Jun;93(7):1819–27.
7) Rossi R, Bauer NH, Becke-Jakob K, Grab D, Herting E, Mitschdörfer B, et al. Empfehlungen für die strukturellen Voraussetzungen der perinatologischen Versorgung in Deutschland (Entwicklungsstufe S2k, AWMF-Leitlinien-Register Nr. 087–001, März 2021). Z Für Geburtshilfe Neonatol. 2021 Aug;225(04):306–19.
8) Qualitätssicherungs-Richtlinie Früh- und Reifgeborene – Gemeinsamer Bundesausschuss [Internet]. [cited 2024 May 1]. Available from: https://www.g-ba.de/richtlinien/41/
9) Adams M, Borradori-Tolsa C, Bickle-Graz M, Grunt S, Weber P, Capone Mori A, et al. Follow-up assessment of high-risk newborns in Switzerland. Paediatrica. 2014;6–10.
10) Bundesamt für Statistik. Gesundheit der Neugeborenen [Internet]. [cited 2024 May 1]. Available from: https://www.bfs.admin.ch/bfs/de/home/statistiken/gesundheit/gesundheitszustand/gesundheit-neugeborene.html
11) Marlow N, Ni Y, Lancaster R, Suonpera E, Bernardi M, Fahy A, et al. No change in neurodevelopment at 11 years after extremely preterm birth. Arch Dis Child Fetal Neonatal Ed. 2021 Jul;106(4):418–24.
12) Johnson S, Wolke D. Behavioural outcomes and psychopathology during adolescence. Early Hum Dev. 2013 Apr;89(4):199–207.
13) Van Noort-van Der Spek IL, Franken MCJP, Weisglas-Kuperus N. Language Functions in Preterm-Born Children: A Systematic Review and Meta-analysis. Pediatrics. 2012 Apr 1;129(4):745–54.
14) Mulder H, Pitchford NJ, Marlow N. Processing speed and working memory underlie academic attainment in very preterm children. Arch Dis Child - Fetal Neonatal Ed. 2010 Jul 1;95(4):F267–72.
15) Rysavy MA, Li L, Bell EF, Das A, Hintz SR, Stoll BJ, et al. Between-hospital variation in treatment and outcomes in extremely preterm infants. N Engl J Med. 2015 May 7;372(19):1801–11.
16) Pittet-Metrailler MP, Mürner-Lavanchy I, Adams M, Bickle-Graz M, Pfister RE, Natalucci G, et al. Neurodevelopmental outcome at early school age in a Swiss national cohort of very preterm children. Swiss Med Wkly [Internet]. 2019 Jun 2 [cited 2022 Nov 8];(21). Available from: https://smw.ch/article/doi/smw.2019.20084
17) Twilhaar ES, Pierrat V, Marchand-Martin L, Benhammou V, Kaminski M, Ancel PY. Profiles of Functioning in 5.5-Year-Old Very Preterm Born Children in France: The EPIPAGE-2 Study. J Am Acad Child Adolesc Psychiatry. 2022 Jul;61(7):881–91.
18) Ahearne CE, Boylan GB, Murray DM. Short and long term prognosis in perinatal asphyxia: An update. World J Clin Pediatr. 2016 Feb 8;5(1):67–74.
19) Robertsson Grossmann K, Eriksson Westblad M, Blennow M, Lindström K. Outcome at early school age and adolescence after hypothermia-treated hypoxic-ischaemic encephalopathy: an observational, population-based study. Arch Dis Child Fetal Neonatal Ed. 2023 May;108(3):295–301.
20) Conway JM, Walsh BH, Boylan GB, Murray DM. Mild hypoxic ischaemic encephalopathy and long term neurodevelopmental outcome – A systematic review. Early Hum Dev. 2018 May 1;120:80–7.
21) Pappas A, Milano G, Chalak LF. Hypoxic-Ischemic Encephalopathy: Changing Outcomes Across the Spectrum. Neurol Dev Outcomes High-Risk Neonates. 2023 Mar 1;50(1):31–52.
22) Robb TJ, Tonks J, Spencer APC, Jary S, Whitfield CK, Thoresen M, et al. Communication skills in children aged 6–8 years, without cerebral palsy cooled for neonatal hypoxic-ischemic encephalopathy. Sci Rep. 2022 Oct 22;12(1):17757.
23) Edmonds CJ, Cianfaglione R, Cornforth C, Vollmer B. Children with neonatal Hypoxic Ischaemic Encephalopathy (HIE) treated with therapeutic hypothermia are not as school ready as their peers. Acta Paediatr Oslo Nor 1992. 2021 Oct;110(10):2756–65.
24) Cainelli E, Vedovelli L, Mastretta E, Gregori D, Suppiej A, Bisiacchi PS. Long-Term Outcomes after Neonatal Hypoxic-Ischemic Encephalopathy in the Era of Therapeutic Hypothermia: A Longitudinal, Prospective, Multicenter Case-Control Study in Children without Overt Brain Damage. Child Basel Switz. 2021 Nov 22;8(11):1076.
25) Victor S, Rocha-Ferreira E, Rahim A, Hagberg H, Edwards D. New possibilities for neuroprotection in neonatal hypoxic-ischemic encephalopathy. Eur J Pediatr. 2022 Mar;181(3):875–87.
26) Wu YW, Comstock BA, Gonzalez FF, Mayock DE, Goodman AM, Maitre NL, et al. Trial of Erythropoietin for Hypoxic-Ischemic Encephalopathy in Newborns. N Engl J Med. 2022 Jul 14;387(2):148–59.
27) Schwerzmann M, Schwitz F, Thomet C, Kadner A, Pfammatter JP, Wustmann K. Challenges of congenital heart disease in grown-up patients. Swiss Med Wkly. 2017;147:w14495.
28) Liu Y, Chen S, Zühlke L, Black GC, Choy M kit, Li N, et al. Global birth prevalence of congenital heart defects 1970–2017: updated systematic review and meta-analysis of 260 studies. Int J Epidemiol. 2019 Apr;48(2):455–63.
29) Latal B. Neurodevelopmental Outcomes of the Child with Congenital Heart Disease. Clin Perinatol. 2016 Mar 1;43(1):173–85.
30) Knowles RL, Tadic V, Hogan A, Bull C, Rahi JS, Dezateux C, et al. Self-Reported Health Experiences of Children Living with Congenital Heart Defects: Including Patient-Reported Outcomes in a National Cohort Study. PLOS ONE. 2016 Aug 3;11(8):e0159326.
31) Sanz JH, Wang J, Berl MM, Armour AC, Cheng YI, Donofrio MT. Executive Function and Psychosocial Quality of Life in School Age Children with Congenital Heart Disease. J Pediatr. 2018 Nov 1;202:63–9.
32) Abda A, Bolduc ME, Tsimicalis A, Rennick J, Vatcher D, Brossard-Racine M. Psychosocial Outcomes of Children and Adolescents With Severe Congenital Heart Defect: A Systematic Review and Meta-Analysis. J Pediatr Psychol. 2019 May 1;44(4):463–77.
33) Mills R, McCusker CG, Tennyson C, Hanna D. Neuropsychological outcomes in CHD beyond childhood: a meta-analysis. Cardiol Young. 2018 Mar;28(3):421–31.
34) Feldmann M, Bataillard C, Ehrler M, Ullrich C, Knirsch W, Gosteli-Peter MA, et al. Cognitive and Executive Function in Congenital Heart Disease: A Meta-analysis. Pediatrics. 2021 Oct 1;148(4):e2021050875.
35) Ware J, Butcher JL, Latal B, Sadhwani A, Rollins CK, Brosig Soto CL, et al. Neurodevelopmental evaluation strategies for children with congenital heart disease aged birth through 5 years: recommendations from the cardiac neurodevelopmental outcome collaborative. Cardiol Young. 2020 Nov;30(11):1609–22.
36) Sood E, Newburger JW, Anixt JS, Cassidy AR, Jackson JL, Jonas RA, et al. Neurodevelopmental Outcomes for Individuals With Congenital Heart Disease: Updates in Neuroprotection, Risk-Stratification, Evaluation, and Management: A Scientific Statement From the American Heart Association. Circulation. 2024 Mar 26;149(13):e997–1022.
37) Natterer J, Schneider J, Sekarski N, Rathke V, Adams M, Latal B, et al. ORCHID (Outcome Registry for CHIldren with severe congenital heart Disease) a Swiss, nationwide, prospective, population-based, neurodevelopmental paediatric patient registry: framework, regulations and implementation. Swiss Med Wkly [Internet]. 2022 Sep 2 [cited 2022 Nov 6];(35). Available from: https://smw.ch/article/doi/smw.2022.w30217
38) Cassidy AR, Ilardi D, Bowen SR, Hampton LE, Heinrich KP, Loman MM, et al. Congenital heart disease: A primer for the pediatric neuropsychologist. Child Neuropsychol. 2018 Oct 3;24(7):859–902.
39) Johnson S, Marlow N. Early and long-term outcome of infants born extremely preterm. Arch Dis Child. 2017 Jan 1;102(1):97–102.
40) Schreglmann M, Ground A, Vollmer B, Johnson MJ. Systematic review: long-term cognitive and behavioural outcomes of

neonatal hypoxic–ischaemic encephalopathy in children without cerebral palsy. Acta Paediatr. 2020;109(1):20–30.

41) Spillmann R, Polentarutti S, Ehrler M, Kretschmar O, Wehrle FM, Latal B. Congenital heart disease in school-aged children: Cognition, education, and participation in leisure activities. Pediatr Res. 2023 Oct;94(4):1523–9.

42) Wehrle FM, Bartal T, Adams M, Bassler D, Hagmann CF, Kretschmar O, et al. Similarities and Differences in the Neurodevelopmental Outcome of Children with Congenital Heart Disease and Children Born Very Preterm at School Entry. J Pediatr. 2022 Nov 1;250:29-37.e1.

43) van Beek PE, van der Horst IE, Wetzer J, van Baar AL, Vugs B, Andriessen P. Developmental Trajectories in Very Preterm Born Children Up to 8 Years: A Longitudinal Cohort Study. Front Pediatr. 2021;9:672214.

44) Sanz JH, Anixt J, Bear L, Basken A, Beca J, Marino BS, et al. Characterisation of neurodevelopmental and psychological outcomes in CHD: a research agenda and recommendations from the cardiac neurodevelopmental outcome collaborative. Cardiol Young. 2021 Jun;31(6):876–87.

45) Feldmann M, Rousson V, Nguyen TD, Bernet V, Hagmann C, Latal B, et al. Cognitive outcome of early school-aged children born very preterm is not predicted by early short-term amplitude-integrated electroencephalography. Acta Paediatr. 2019 Jul;109(1):78–84.

46) Anderson PJ, Treyvaud K, Spittle AJ. Early developmental interventions for infants born very preterm - what works? Semin Fetal Neonatal Med. 2020 Jun;25(3):101119.

47) Cioni G, Inguaggiato E, Sgandurra G. Early intervention in neurodevelopmental disorders: underlying neural mechanisms. Dev Med Child Neurol. 2016 Mar;58 Suppl 4:61–6.

48) Clark BG, Acton BV, Alton GY, Joffe AR, Dinu IA, Robertson CMT. Screening for language delay after life-saving therapies in term-born infants. Cardiol Young. 2016 Oct;26(7):1343–51.

49) Spittle A, Orton J, Anderson PJ, Boyd R, Doyle LW. Early developmental intervention programmes provided post hospital discharge to prevent motor and cognitive impairment in preterm infants. Cochrane Database Syst Rev. 2015 Nov 24;2015(11):CD005495.

50) Anderson LM, Shinn C, Fullilove MT, Scrimshaw SC, Fielding JE, Normand J, et al. The effectiveness of early childhood development programs. A systematic review. Am J Prev Med. 2003 Apr;24(3 Suppl):32–46.

51) Conti G, Heckman J, Pinto R. The Effects of Two Influential Early Childhood Interventions on Health and Healthy Behaviour. Econ J Lond Engl. 2016 Oct;126(596):F28–65.

52) Kaaresen PI, Rønning JA, Ulvund SE, Dahl LB. A randomized, controlled trial of the effectiveness of an early-intervention program in reducing parenting stress after preterm birth. Pediatrics. 2006 Jul;118(1):e9-19.

53) Spittle AJ, Anderson PJ, Lee KJ, Ferretti C, Eeles A, Orton J, et al. Preventive care at home for very preterm infants improves infant and caregiver outcomes at 2 years. Pediatrics. 2010 Jul;126(1):e171-178.

54) Reynolds AJ, Temple JA, White BAB, Ou SR, Robertson DL. Age 26 cost-benefit analysis of the child-parent center early education program. Child Dev. 2011;82(1):379–404.

55) Rolnick A, Grunewald R. Early Child Dev Econ Dev High Public Return. 2003;(Minneapolis: The Federal Reserve Bank of Minneapolis.):6–12.

56) Guralnick MJ. Early Intervention for Children with Intellectual Disabilities: An Update. J Appl Res Intellect Disabil JARID. 2017 Mar;30(2):211–29.

57) Morgan C, Fetters L, Adde L, Badawi N, Bancale A, Boyd RN, et al. Early Intervention for Children Aged 0 to 2 Years With or at High Risk of Cerebral Palsy: International Clinical Practice Guideline Based on Systematic Reviews. JAMA Pediatr. 2021 Aug 1;175(8):846–58.

58) Müllner C. Entwicklungsnachsorge von Frühgeborenen: Outcome und Evaluation des Follow-Up unter Berücksichtigung der elterlichen Perspektive. Universität Zürich; 2023.

59) Birkenmaier A, Adams M, Kleber M, Schwendener Scholl K, Rathke V, Hagmann C, et al. Increase in Standardized Management of Neonates with Hypoxic-Ischemic Encephalopathy Since Implementation of a Patient Register. Ther Hypothermia Temp Manag. 2023 Dec 1;13(4):175–83.

60) Adams M, Schulzke SM, Natalucci G, Schneider J, Riedel T, Tolsa CB, et al. Outcomes for Infants Born in Perinatal Centers Performing Fewer Surgical Ligations for Patent Ductus Arteriosus: A Swiss Population-Based Study. J Pediatr. 2021 Oct;237:213-220.e2.

61) Natalucci G, Latal B, Koller B, Rüegger C, Sick B, Held L, et al. Neurodevelopmental Outcomes at Age 5 Years After Prophylactic Early High-Dose Recombinant Human Erythropoietin for Neuroprotection in Very Preterm Infants. JAMA. 2020 Dec 8;324(22):2324–7.

62) Barrington KJ. The adverse neuro-developmental effects of postnatal steroids in the preterm infant: a systematic review of RCTs. BMC Pediatr. 2001;1:1.

63) Adams M, Hoehre TC, Bucher HU, Swiss Neonatal Network. The Swiss Neonatal Quality Cycle, a monitor for clinical performance and tool for quality improvement. BMC Pediatr. 2013 Sep 28;13:152.

64) the Swiss Neonatal Network & Follow-up Group, Adams M, Natalucci G, Bassler D. An overview of the Swiss Neonatal Network & Follow-up Group (SwissNeoNet). Pediatr Med. 2023 Feb;6:7–7.

65) Steurer MA, Adams M, Bacchetti P, Schulzke SM, Roth-Kleiner M, Berger TM, et al. Swiss medical centres vary significantly when it comes to outcomes of neonates with a very low gestational age. Acta Paediatr Oslo Nor 1992. 2015 Sep;104(9):872–9.

66) Adams M, Brotschi B, Birkenmaier A, Schwendener K, Rathke V, Kleber M, et al. Process variations between Swiss units treating neonates with hypoxic-ischemic encephalopathy and their effect on short-term outcome. J Perinatol Off J Calif Perinat Assoc. 2021 Dec;41(12):2804–12.

67) Grass B, Brotschi B, Hagmann C, Birkenmaier A, Schwendener K, Adams M, et al. Centre-specific differences in short-term outcomes in neonates with hypoxic-ischaemic encephalopathy. Swiss Med Wkly. 2021 Mar 29;151:w20489.

68) Norman M, Håkansson S, Kusuda S, Vento M, Lehtonen L, Reichman B, et al. Neonatal Outcomes in Very Preterm Infants With Severe Congenital Heart Defects: An International Cohort Study. J Am Heart Assoc. 2020 Mar 3;9(5):e015369.

69) Adams M, Bassler D, Bucher HU, Roth-Kleiner M, Berger TM, Braun J, et al. Variability of Very Low Birth Weight Infant Outcome and Practice in Swiss and US Neonatal Units. Pediatrics. 2018 May;141(5):e20173436.

70) Seaton SE, Draper ES, Adams M, Kusuda S, Håkansson S, Helenius K, et al. Variations in Neonatal Length of Stay of Babies Born Extremely Preterm: An International Comparison Between iNeo Networks. J Pediatr. 2021 Jun;233:26-32.e6.

71) Grass B, Scheidegger S, Latal B, Hagmann C, Held U, Brotschi B, et al. Short-term neurological improvement in neonates with hypoxic-ischemic encephalopathy predicts neurodevelopmental outcome at 18-24 months. J Perinat Med. 2020 Mar 26;48(3):296–303.

72) El Faleh I, Faouzi M, Adams M, Gerull R, Chnayna J, Giannoni E, et al. Bronchopulmonary dysplasia: a predictive scoring system for very low birth weight infants. A diagnostic accuracy study with prospective data collection. Eur J Pediatr. 2021 Aug;180(8):2453–61.

73) Adams M, Schulzke SM, Rogdo B, Meyer P, McDougall J, Stocker M, et al. Impact of SARS-CoV-2 on incidence, treatment and outcome of very preterm born infants in Switzerland: a retrospective, population-based cohort study. Swiss Med Wkly. 2022 May 9;152:w30174.

74) Bayley N. Bayley scales of infant and toddler development. Administration manual. third. San Antonio, TX: Harcourt; 2006.

75) Palisano R, Rosenbaum P, Walter S, Russell D, Wood E, Galuppi B. Development and reliability of a system to classify gross motor function in children with cerebral palsy. Dev Med Child Neurol. 1997 Apr;39(4):214–23.

76) Kaufman A, Kaufman N. KABC-II. Kaufman Assessment Battery for Children – II (Deutschsprachige Fassung von Peter Melchers und Martin Melchers). 2015.

77) Wechsler D. Wechsler Preschool and Primary Scale of Intelligence. 4th ed. Deutsche Bearbeitung. Petermann F, Daseking M, editors. Frankfurt, Germany; 2018.

78) Zürcher Neuromotorik-2. Zürich] Akademie Für das Kind Giedion Risch [2019; 2019. 1 p.

79) Goodman R. The Strengths and Difficulties Questionnaire: a research note. J Child Psychol Psychiatry. 1997 Jul;38(5):581–6.

80) Largo RH, Pfister D, Molinari L, Kundu S, Lipp A, Duc G. Significance of prenatal, perinatal and postnatal factors in the development of AGA preterm infants at five to seven years. Dev Med Child Neurol. 1989 Aug;31(4):440–56.

81) Edwards EM, Greenberg LT, Horbar JD, Gagliardi L, Adams M, Berger A, et al. Discharge Age and Weight for Very Preterm Infants in Six Countries: 2012-2020. Neonatology. 2023;120(2):208–16.

82) Macarthur C, Walsh CM, Buchanan F, Karoly A, Pires L, McCreath G, et al. Development of the patient-oriented research curriculum in child health (PORCCH). Res Involv Engagem. 2021 May 10;7(1):27.