SHIPS – **S**creening to improve **H**ealth **I**n very **P**reterm infant**S** in Europe

CARE, DEVELOPMENT AND HEALTH OF CHILDREN BORN VERY PRETERM AT 5 YEARS OF AGE

Introduction to SHIPS

Supporting children born very preterm and their parents

Medical advances for the care of babies born very preterm, meaning before the 32nd week of gestation, have led to increased survival and a decrease in major neonatal complications. Most children born very preterm have normal development and good health, but some experience difficulties. These difficulties are diverse and can include developmental, speech or motor delays or vision, hearing or respiratory problems. Early detection of these problems makes it possible to intervene and to provide information and support for parents.

While we know a lot about the early care of babies born very preterm, much less is known about the care that children receive after they leave the neonatal unit. Many children are enrolled in follow-up programmes to support their development. However, these programmes differ among countries, and we have little information about whether all families access these services and how long they use them.

The ‘**S**creening to improve **H**ealth **I**n very **P**reterm Infant**S** in Europe’ (SHIPS) project had a mission to study the availability and use of evidence-based* health care, follow-up and prevention programmes for children born very preterm. The project is a European research collaboration which includes 6792 children born before 32 weeks of pregnancy in 19 regions in 11 European countries.

19 regions (yellow) in 11 EU countries (blue) participated in SHIPS: Belgium, Denmark, Estonia, France, Germany, Italy, the Netherlands, Poland, Portugal, Sweden, United Kingdom

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* Evidence-based health care is a way of providing health care that is guided by a thoughtful integration of the best available scientific knowledge with clinical expertise.

The SHIPS partners collected data in the study regions on four major topics:

1. Children's health, healthcare use and quality of life
2. Children's cognitive and motor development
3. Families' experiences of follow-up and subsequent care
4. Coverage, content and costs of follow-up programmes.

The data collection took place when the children were five years old and consisted of four different studies. One of those is the 'Study of Health and Wellbeing at age 5'. The results of this particular study will be covered in this brochure.

Results of the Study of Health and Wellbeing at 5 Years of Age

The 'Study of Health and Wellbeing at age 5' explored health and child development, family wellbeing and use of health services (routine follow-up, emergency visits, hospitalisation) with a parental questionnaire. The results were grouped into four categories:

FOLLOW-UP POLICIES

USE OF HEALTH CARE SERVICES

CARE EQUITY

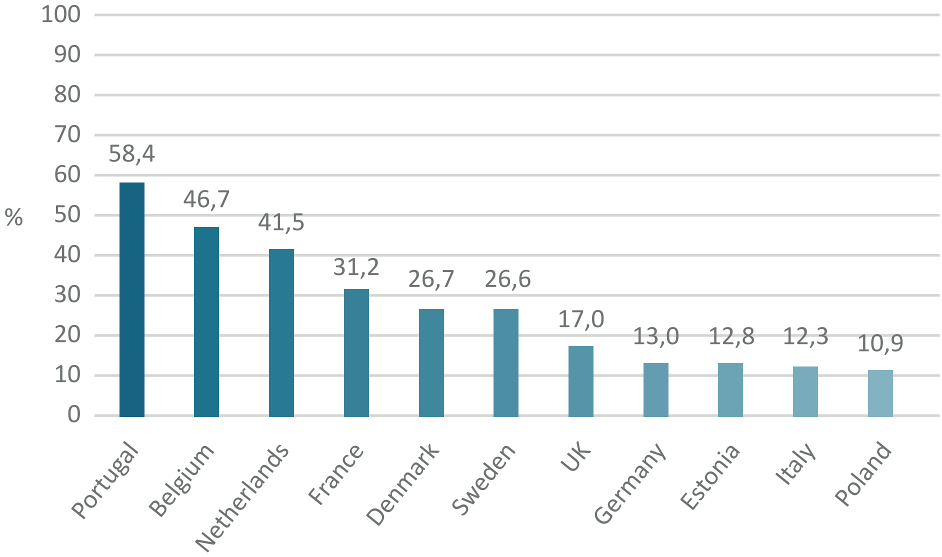
PARENT'S VIEWS AND EXPERIENCES OF CARE

Follow-Up Policies

There were large variations in follow-up services across countries. The proportion of children included in follow-up programmes and follow-up duration were different across the study countries, regions, and sometimes even hospitals.

→ Although routine follow-up was offered to most children born very preterm, less than 1 of 3 children was still having special follow-up visits for preterm children at five years of age. The percentage of children using follow-up was highest where follow-up was nationally or regionally recommended until five years of age (Portugal, Belgium, the Netherlands, France and Sweden).

→ Depending on the country, the percentage of children who had never used follow-up services varied between 0% - 22%. It is important to remember that the SHIPS data come from participating regions in each country, but there is likely variation between regions within countries.



Percentage of children still using routine follow-up services at 5 years of age

Use of Health Care Services

Many children were frequent users of a range of different health care services at five years of age.

- → 29% of parents reported that their child had seen one specialist over the past year and 42% had seen two or more different specialists, such as eye or hearing specialists, speech therapists or physiotherapists.
- → In countries with more extensive preterm follow-up programmes (where more children are still participating in routine follow-up at five years of age), children were less likely to rely on outpatient and emergency room services and being hospitalised.

Parent statements

> *It’s nice to have someone follow you. Even if there was nothing serious for us, we were still followed, so I thought within myself, if there was something they would have detected it quickly.*

> *Big disappointment that no one has overall responsibility for follow-up. Our daughter has many doctor visits at three different hospitals. Countless visits could have been avoided if someone had an overview of the situation.*

Care Equity

There may be social or geographic inequities in the care and follow-up of children born very preterm.

- Children born very preterm with social risk factors, such as having a mother with a low educational level or who was foreign-born, may have received less optimal care at five years of age. They were more likely to rely on outpatient care and emergency room services and to be hospitalised, but less likely to consult medical specialists.

- Children with social risk factors were also less likely to use routine follow-up services for children born very preterm, which could explain why they were using less specialist services and had more visits to the hospital.

- The availability of follow-up may also differ for families living far from urban centres, as remarked by some parents:

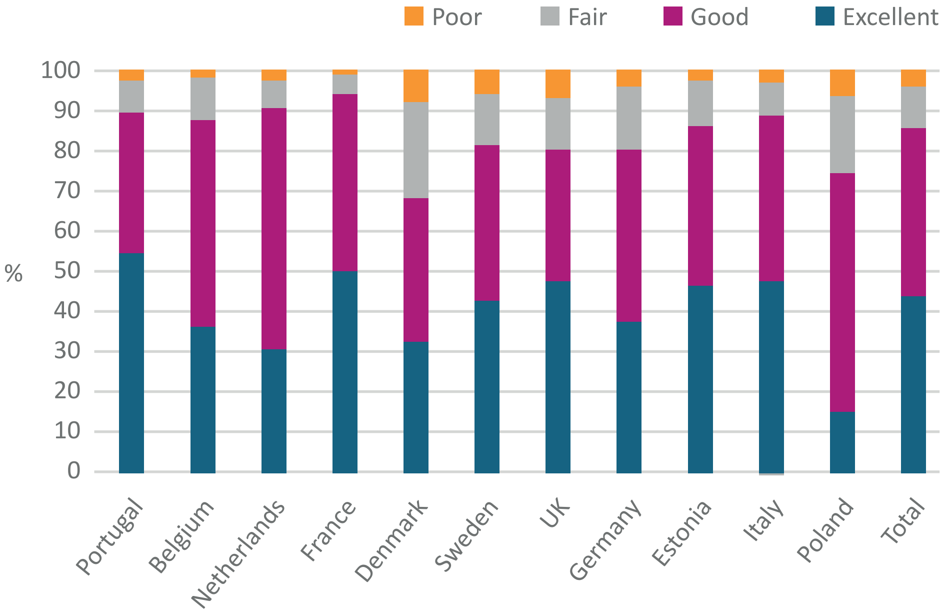
Parent statement

> *Unfortunately, help for premature babies is only available in larger cities. We live in the countryside and have limited access to all specialists. A visit to a specialist is associated with an additional trip, and I do not always have a transport and unfortunately there is still a very long waiting time for some specialists.*

Parents’ Views and Experiences of Care

The majority of parents rated the healthcare received by their children as good or excellent.

- → Although satisfaction with care was high overall, it varied across countries. Between 68% and 94% of parents rated the care their child received as good or excellent.
- → The parents who were the least satisfied were those whose children had health and developmental problems: about one-third of these parents rated care as fair or poor. This suggests that health systems should focus on improving the care for children with complex care needs.



Parents’ ratings of care after discharge from the neonatal unit by country

In Conclusion

There may be social or geographic inequities in the care and follow-up of children born very preterm.

1. Because follow-up programmes aim to facilitate access to care and interventions, having continued follow-up until five years could help families to receive the most appropriate care for their children born very preterm.

2. Families with social risk factors were less likely to use routine follow-up services for children born very preterm.

3. There are many aspects in the long-term care for children born very preterm that can be improved in all the 11 study countries, including standardised content and duration of follow-up, ensuring care coordination and promoting better communication between parents and care providers.

4. More research is needed on optimal follow-up for children born very preterm and their parents. This research should include the opinions and life experiences of preterm individuals and their families.

Why are these Results important?

The results indicate large variations in follow-up care of children born very preterm in Europe. It is important to highlight this not only for parents and children, but also for healthcare professionals involved in follow-up care, because follow-up programmes offer several benefits and advantages:

For parents: Follow-up programmes give insights into the child's health conditions and development. Moreover, tailored care for children born very preterm may reduce the health-related burden and costs for families and increase their quality of life.

For very preterm children: Follow-up programmes facilitate early identification of children in need of support and initiate adequate support. Especially in the areas of attention, memory, and learning, children born very preterm may have challenges which potentially impact life-long emotional well-being and performance.

For follow-up teams and healthcare professionals: Follow-up programmes facilitate early identification of children in need of support and timely referral. Follow-up can also represent an opportunity for professional growth when the results of follow-up are recorded and discussed within the team.

For health systems, policy and research: By proving better organised care, follow-up can also help to avoid unnecessary consultations and hospitalisations and improve the quality of care. Follow-up programmes provide information on children's development that help to improve neonatal care and support research to improve the development and potential of infants born very preterm.

SHIPS in the Future

The SHIPS team is working hard to keep the project going and encourages all parents in taking part in another follow-up study and to stay tuned for updates. The data collected from SHIPS will be integrated into the European RECAP preterm data platform. This platform will allow researchers to find out about existing European studies on children and adults born very preterm or with very low birth weight over the past 30 years and to use anonymised data to answer questions about very preterm health and development that cannot be answered by national studies only. Find out more about RECAP preterm at **www.recap-preterm.eu**.

Learn more

If you would like to learn more about SHIPS, all people and institutions involved and the parents section or if you are interested in the results of the other SHIPS studies, visit us at **www.epiceproject.eu/en**. Several scientific articles, already published in renowned journals, have been summarised for you there. And there is more to come.

Thank you

Sincere thanks to all parents and children who joined the SHIPS study. Only because of your participation we have been able to describe the follow-up and health care received by children born very preterm and fill gaps in the current scientific knowledge. Your participation made data available which is needed to raise awareness and facilitate discussion to improve the follow-up situation for children in Europe and makes a difference for future families. We also want to thank the SHIPS Parental Advisory Board for their suggestions and the project members for their collaboration.

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