



LE GOUVERNEMENT  
DU GRAND-DUCHÉ DE LUXEMBOURG  
Ministère de la Santé

Direction de la Santé



LUXEMBOURG  
INSTITUTE  
OF HEALTH  
RESEARCH DEDICATED TO LIFE

# Susana

## Pour la santé des bébés et des mamans

Le système de Surveillance de la Santé autour de la Naissance au Luxembourg

## Für die Gesundheit von Kind und Mutter

Das Luxemburger System der Gesundheitsüberwachung rundum die Geburt

## For the health of new borns and mothers

The Perinatal Health monitoring System in Luxembourg

## Para a saúde dos bebés e das mães

O sistema de Vigilância da Saúde relativa aos Nascimento no Luxemburgo



# Susana

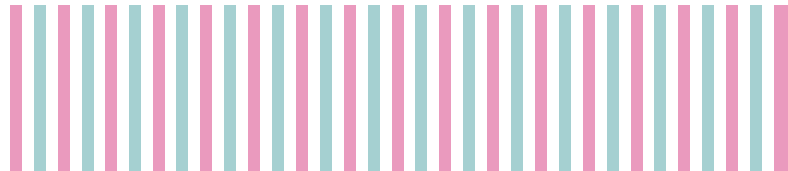
## For the health of new borns and mothers

The Perinatal Health monitoring System in Luxembourg

## What is Susana for?

**Susana** is an exhaustive comprehensive monitoring registry that helps to:

- › Outline an overall **view of the health** of mothers and newborn.
- › **Identify health risks**, at national and international level, and prioritize preventive actions targeting identified risks.
- › **Follow up the treatment and the quality of care provided** to mothers and newborns in Luxembourg in order to implement improvements, if necessary.
- › Track **the evolution of perinatal health in Luxembourg** over time.
- › **Meet the demands of international organizations** like the World Health Organisation (WHO), EuroPeristat, Organisation for Economic Co-operation and Development (OECD) and hence to compare them to the national results.
- › **Set up programmes and actions for prevention and health promotion** based on the results obtained.
- › Answer scientific research questions.



# What is the Susana registry?

Since 1980, all national maternity hospitals and liberal midwives contribute to data collection on the health of mothers and newborns. The **Susana** registry is placed under the responsibility of the Ministry of Health. It has been developed by the PERINAT National Committee, composed of gynaecologists, neonatologists, paediatricians, midwives, nurses, as well as members of the Luxembourg Institute of Health (LIH) and the Directorate of Health.

This programme collects information on:

- > **The health of mother during their pregnancy and labour.**
- > **The health of the newborn at the onset of birth, and the first days after birth and, if necessary, during their stay in a neonatology service.**



# What informations are collected?

The collected informations meet the recommendations of the World Health Organisation (WHO), the European group EuroPeristat and the national requirements defined by the PERINAT National Committee.

- › Susana questions are requested only for public health purposes and are used to identify factors that may have an effect on perinatal health.
- › **During a prenatal visit or upon your arrival at the maternity hospital**, your midwife or gynaecologist will ask you some questions about your health, lifestyle, family situation, professional life, and obstetrical records.
- › The health care professionals in charge of your treatment will collect other information directly from your medical file concerning your labour.

*Did you give birth by a caesarean section?*

*Did you take an epidural anaesthesia?*

*How was the baby born?  
(head, seat, etc.)*

*Did your baby need a transfer to a neonatology service?*

A few examples of possible questions



# How is the data collection carried out?

**The data will be entered in a secure computer programme,** and then processed with other data from all births in Luxembourg.

**The data will never be analysed individually.**

Examples of results obtained:

- > % of caesarean sections in Luxembourg;
- > % of epidural anaesthesia injections in Luxembourg;
- > % of diabetic mothers.

As your contribution to this registry is voluntary, **you are free not to answer the questions. This will not influence your care during your stay at the maternity hospital.**





## What are your rights?

You have the right to access and rectify your personal data. In some cases (depending on the conditions set by the law), you also have additional rights to oppose the way your data is used, to request the deletion of your data, to request the restriction of certain aspects of your data processing, to recover your data in order to transmit them to a third-party (right to portability).

Finally, you also have the right to lodge a complaint at the *Commission Nationale pour la Protection des Données* (CNPD) (National Data Protection Commission) concerning the processing of your personal data.

If you wish to exercise your rights, you can contact the project manager or his/her appointed representative.

If you need further information concerning the processing of your personal data by the LIH, you can contact:

› the data protection officer of the **LIH** by e-mail at **dpo@lih.lu**

› the data protection officer of the **Ministry of Health** by e-mail at **info\_donnees@ms.etat.lu**

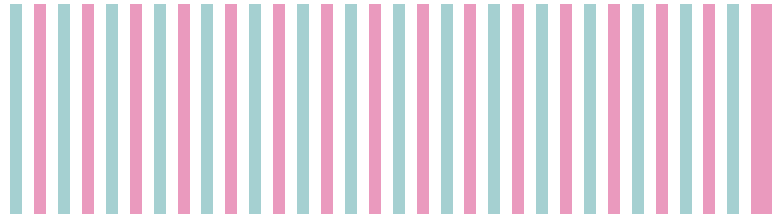




# Susana: a collection of secure and confidential information on what legal basis?

According to the General European Data Protection Regulation (GDPR), **the use of your personal data is necessary for reasons of public interest** (art. 6.1-e) and **in the interest of population in the domain of public health** (art. 9.2-i).

**Your data will be processed in a strictly confidential manner**, in accordance with the law of 1<sup>st</sup> August 2018, on the organisation of the National Data Protection Commission and the implementation of the regulation (EU) 2016/679 of the European Parliament, as well as of the Council of 27<sup>th</sup> April 2016, on the protection of natural persons with regard to the processing of personal data and the free circulation of such data.





# What will happen to my data and my baby's data?

Your data will be analysed with those of other mothers and babies born in Luxembourg (in an aggregated manner) by the Luxembourg Institute of Health (LIH).

Following the processing of this information, a report concerning the perinatal health monitoring and indicators will be issued.

Your data will be stored for 20 years.

**The LIH implements appropriate security measures to protect your data against the risks of unauthorised access, loss, misuse, disclosure, alteration or destruction.**

Your data will be pseudonymised, this means that your data will be linked to that is, a confidential reference code instead of your name. This code does not permit to identify you and will only facilitate the processing of your data for scientific purposes. **Your identity will never appear** in a document intended for the public or other institutions.

**Only the scientific team working on the project at the LIH has access to these pseudonymised data.**





# Susana



« Just being born is like  
receiving the whole  
world as a gift »

*Jostein Gaarder*

FR

## Où pouvez-vous retrouver les résultats de Susana ?

Les résultats sont accessibles:

- > sur le portail santé **www.sante.lu**
- > sur le site **www.susana.lu**

## En cas de question, à qui pouvez-vous vous adresser ?

À tout moment vous pouvez adresser vos questions:

- > **À la maternité où vous avez accouché**, en s'adressant au responsable
- > **Au Luxembourg Institute of Health (LIH)**, à la responsable du projet, Aline Lecomte  
Tél: **+352 26 970 882**
- > **À la Direction de la Santé du Luxembourg**, au responsable du programme Susana, Guy Weber  
Tél: **+352 247 755 64**

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## Wo können Sie die Ergebnisse aus dem Register Susana finden?

Die Ergebnisse sind zu finden:

- > auf dem Gesundheitsportal **www.sante.lu**
- > auf der Seite **www.susana.lu**

## An wen können Sie sich bei Fragen wenden?

Sie können Ihre Fragen jederzeit richten an:

- > **Das Krankenhaus, in dem Sie entbunden haben**, wenden Sie sich an den Leiter
- > **Das Luxembourg Institute of Health (LIH)**, wenden Sie sich an die Projektleiterin, Aline Lecomte  
Tel: **+352 26 970 882**
- > **Die Direktion für Gesundheit**, an den Leiter des Programms Susana, Guy Weber  
Tel: **+352 247 755 64**

EN

## Where can you find the results from "Susana"?

The results are available:

- > at the health portal **www.sante.lu**
- > at the Susana website **www.susana.lu**

## Who to contact if you have any questions?

You can send your questions to:

- > **The maternity hospital where your baby was born**, by contacting the manager
- > **The Luxembourg Institute of Health (LIH)**, the project manager, Aline Lecomte  
Tel: **+352 26 970 882**
- > **The Health Directorate**, the Susana programme manager, Guy Weber  
Tel: **+352 247 755 64**

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## Onde pode encontrar os resultados do Susana?

Os resultados estão acessíveis:

- > no portal da saúde **www.sante.lu**
- > no site **www.susana.lu**

## Em caso de dúvida, quem posso contactar?

Pode colocar as suas dúvidas a qualquer momento:

- > **À maternidade que a assistiu no parto**, dirigindo-se ao responsável
- > **Ao Luxembourg Institute of Health (LIH)**, à responsável do projeto, Aline Lecomte  
Tel: **+352 26 970 882**
- > **À Direção da Saúde**, ao responsável do programa Susana, Guy Weber  
Tel: **+352 247 755 64**

