

Appendix: Translated excerpts from the RIFs

RIF – standard version – translated excerpt from page 1

Dear...,

In this information letter we ask you to give a tube of blood to the Sophia Biobank. This blood can then be used for medical-scientific research. You can decide for yourself, in consultation with your parents and/or legal guardian, if you want to donate blood. Before you make a decision, it is important to know more about the Sophia Biobank. Read this information letter carefully and well. You can discuss the information with your parents or others and of course you will have time for consideration. Do you have questions after reading the letter? Then you can contact the employees of the Sophia Biobank. Further down in this letter you will find the contact details.

What is the aim of the Sophia Biobank?

The aim of the Sophia Biobank is collecting data and blood from children. This way, more and better medical-scientific research on diseases of children can be done. Because all departments in the Erasmus MC-Sophia collaborate in this, we will find out more about diseases of children and the treatments of those.

Who can participate in the Sophia Biobank?

To do research with ill children, we also need to know a lot about healthy children. First we need to know what 'healthy' is, in order to be able to study a certain disease. In research language we call that a 'healthy control group'.

You are in our hospital because you need a surgery. Except for this surgery you are healthy. That is why we ask you and your parents and/or legal guardian if you want to donate blood for the Sophia Biobank.

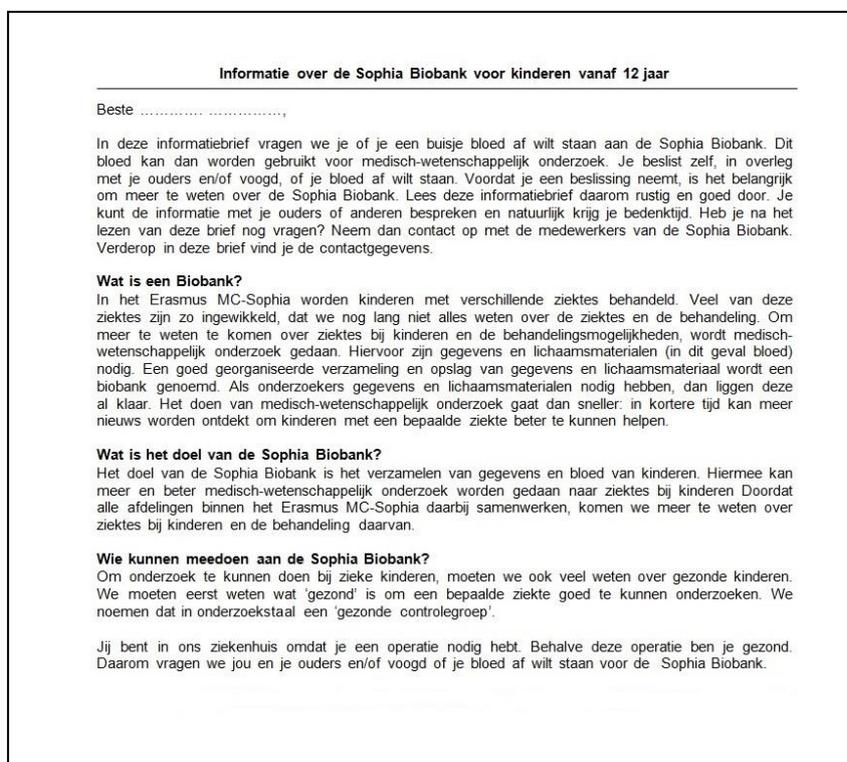


Figure 3: Picture of the excerpt from the standard RIF

RIF – novel version – translated excerpt from page 1

Introduction

We have asked you to participate in scientific research.

In this form you can find all the information that you will need to make a decision.

What is the aim of this research?

What is the Sophia Biobank?

The Sophia Biobank collects blood from children and we also collect information about your health.

The aim of the Sophia Biobank

The aim of the Sophia Biobank is to help researchers to find out:

- How certain diseases originate
- How often these diseases occur
- Why these diseases do or do not respond well to treatment

>> Do you remember what a biobank is? Read about it in Chapter 7 of the comic strip.

Why do we ask you to participate?

You will undergo a surgery, but other than that you are healthy. For the Biobank we collect information and material from healthy children. This way researchers can look for the difference between healthy children and ill children.

>>In chapter 6 of the comic strip you can read more about research with children.

Proefpersonen Informatie Formulier

Introductie
Wij hebben jou gevraagd om mee te doen aan een wetenschappelijk onderzoek.
In dit formulier staat de informatie die je nodig hebt bij het maken van een keuze.

Wat is het doel van dit onderzoek?
Wat is de Sophia Biobank?
De Sophia Biobank verzamelt bloed van kinderen en we verzamelen ook informatie over je gezondheid.
Het doel van de Sophia Biobank is onderzoekers te helpen uit te zoeken:
• hoe bepaalde ziektes ontstaan
• hoe vaak die ziektes voorkomen
• waarom die ziektes wel of juist niet goed reageren op behandelingen
Weet je nog wat een Biobank is? Het staat in hoofdstuk 7 van de strip.

Waarom vragen we jou om mee te doen?
Jij wordt geopereerd, maar verder ben je gezond. In de Biobank verzamelen we informatie en materiaal van gezonde kinderen. Zo kunnen wetenschappers kijken naar het verschil tussen gezonde en zieke kinderen.
In hoofdstuk 6 van de strip lees je meer over onderzoek met kinderen.

Goedkeuring toetsingscommissie
De Sophia Biobank is goedgekeurd door twee commissies:
1. De Inspectie voor de Gezondheidszorg
2. De Medische Ethische Toetsings Commissie Erasmus MC
In hoofdstuk 3 van de strip lees je meer over toetsingscommissies.

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Figure 2: Picture of the excerpt from the novel RIF

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