**Information letter 12-16 year olds**

**The Core Registry**

Hi ...........................................................

You are receiving this letter because you have a rare hormone or bone condition. We would like to learn more about this condition by collecting information from patients.

This information is collected in a *registry*. Do you also want your information to be collected in the registry? You can read more about the registry and your rights here. Read this carefully, so you can decide what you want. You can take your time to think about it. Your parents will also get information about this registry. You can talk with them, and together you will decide.

**About the Registry**

For this registry, we collect information from the hospital notes in the computer, your medical file. This could be information about your condition, your growth, or your blood test results. Other countries in Europe are also part of this registry.

**Why is this registry important?**

Some hormone and bone conditions are very rare. Because of this, doctors and researchers sometimes have little information about these conditions. By collecting information from across Europe, we can learn much more about these rare conditions. This will help doctors treat patients better.

**How does participation work?**

We would like to collect information from your medical file. You do not need to do anything extra, and you will not need any extra tests. You only need to give permission for your medical information to be collected and stored.

**Your details**

The registry uses a secure website to store information. With a special code your information is stored in the registry. This means that doctors and researchers in the registry will not be able to see that the stored information belongs to you. The information does not include your name. For example, it will say whether you are sick and whether you are taking medication. And measurements of your height and weight. Only the treatment team at your hospital will know which code belongs to you. If another doctor or researcher uses your medical information, they won't know it is yours. They will also not be able to contact you.

If you give permission, you may get an email reminder to fill in a questionnaire.

Your collected information can help researchers study rare conditions. By collecting information from many children, researchers can learn more about these conditions and find the best treatments. The results will be shared in research reports to help doctors and researchers around the world.

Would you like to see your information? You can ask for access to the registry by writing your email on the consent form.

**Benefits and risks**

* There are **no benefits** for you. But by joining the registry, you will help doctors and researchers understand rare conditions better. This can help other children in the future.
* There are no risks if you do not join the registry. You will still receive the same treatment that you would normally receive.

**Important to know:**

* Participation is **not required**
* You can always **stop without having to tell them why**
* You are always allowed to **ask questions**.

**Your rights**

**Do you have to join the registry?**

No, you can **decide for yourself** whether you want to join. If you do not want to join, you do not have to, even if your parents would prefer you to join. If you want to join, put your signature on the form.

 **Stop**

If you want to stop, tell your doctor or nurse. This is called: withdrawing your consent. You do not have to explain why you want to stop. You get the treatment you would normally get. If you ask, we can delete all your data from our records and not use it for future research. But if your data has already been shared with researchers, they are still allowed to use it in their studies.

**Your decision**

Do you want to join? Then you put your signature on the consent form. We also need a signature from your parents or guardians.

**Questions and contact**

Do you have any questions? Talk to your parents or ask your doctor or nurse. You can also write down your questions below or send an email to: registries@lumc.nl

|  |
| --- |
| **Space to write down your questions:** |

**Want to know more?**

|  |  |
| --- | --- |
| Macintosh HD:Users:irenenew:Documents:1. Projects Now:1 Illustration PIF for children - LUMC VIMP DCRF:Illustrations - new - jpg exports DEF:jpg files small with handtekening:kaft-met-schaduw.png | Would you like to know more about research or about your rights?Take a look at [www.kindenonderzoek.nl](http://www.kindenonderzoek.nl)Use a translator tool to translate to your language. |

**Consent form for collection and use of my information for the Core Registry (12-16 year olds)**

* I understand the information. I was able to ask questions, and **my questions were answered**.
* I had **enough time to decide** if I want to join.
* I know that **I do not have to join**.
* I understand that I **can always stop** if I do not want to join anymore.
* I understand that **other doctors and researchers** can see my information. But they will not see **my name** or any other details that shows it is about me.
* Enter your email address here if you want to see the collected information:

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**I want to join the Core Registry.**

**Participant's name**: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Signature: Date: \_\_\_ /\_\_\_ /\_\_\_\_\_\_

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**This part is for the doctor/nurse**

I declare that I have fully informed this patient about the Core Registry.

**Name of doctor or nurse practitioner (or his/her representative):**

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Signature: Date:\_\_\_/\_\_\_/\_\_\_\_\_\_

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*The participant will receive an information letter along with a signed version of the consent form.*