

International health data warehouse for children and adolescents with chronic myeloid leukemia (I-CML-Ped Data Warehouse)

Information letter for minors

You're being treated by Dr/Pr _____ for a disease called chronic myeloid leukemia (CML) and you're receiving appropriate treatment.

Throughout your treatment, the doctors record information about your disease, your treatments and everything else that's going on. Thanks to this information, known as health data, researchers can work to better understand your disease and improve your treatment. All their studies on this health data, which will concern other children like you, will lead to improve the treatment of this disease.

1/What is the I-CML-Ped data warehouse?

Information about your disease, your treatments and everything related to your follow up will be collected, and stored in a specific computer system called the I-CML-Ped data warehouse.

A data warehouse can store a lot of computer data. Researchers can retrieve data from a data warehouse and use it directly for their research.

Some data are not collected in the I-CML-Ped data warehouse, such as your name, surname or address, because researchers don't need it. They can't know who you are, or find you.

The Poitiers University Hospital supports the I-CML-Ped data warehouse. The Poitiers University Hospital has a public-interest mission, which means that its work is useful to everyone.

2/ Who can use the data stored in the I-CML-Ped data warehouse

A limited number of people can have access to the information collected in the I-CML-Ped data warehouse:

- people working at Poitiers University Hospital in charge of the organisation of the data warehouse;
- people in charge of the data warehouse security;
- researchers who have a research project concerning chronic myeloid leukemia. Usually they are members of health establishments, hospitals, research organizations, patient associations or European structures.

The data collected in the I-CML-Ped data warehouse are stored in France. Under authorization, some data could be occasionally shared with a researcher in Europe and, in exceptional cases, outside Europe, in order to improve knowledge of chronic myeloid leukemia.

Health data remain in the I-CML-Ped data warehouse for 20 years and then will be deleted.

3/ What are your rights regarding your data collected in the I-CML-Ped data warehouse

- You have the right to say that you don't want your health data to be stored in the I-CML-Ped data warehouse, but this won't stop doctors from treating you,
- You can ask to see your health data and have it corrected if there's a mistake,
- You have the right to have them deleted from the I-CML-Ped data warehouse, or you can ask to limit their use.

4/ Recourses

As long as you are under 18, your parents could contact the CHU of Poitiers Data Protection Officer by e-mail: dpo@chu-poitiers.fr or by mail: CHU de Poitiers - Direction Générale, Délégué à la Protection des Données - 2 Rue de la Milétrie - 86021 POITIERS CEDEX - France.

If you think that the Poitiers University Hospital has not respected your rights, as long as you are under 18, your parents can write to the Commission Nationale de l'Informatique et des Libertés (CNIL) on the website: <https://www.cnil.fr/plaintes> or by post: CNIL - Service des Plaintes - 3 Place de Fontenoy - TSA 80715 - 75334 PARIS CEDEX 07 France).

When you turn 18, it's up to you to take the necessary steps to assert your rights.

5/ Information

You will not be informed of the research carried out and the results obtained thanks to the I-CML-Ped data warehouse. To find out more about this data warehouse and related research projects, please consult the dedicated internet portal on the Poitiers University Hospital website(<https://www.chu-poitiers.fr/specialites/centre-dinvestigation-clinique/axe-thor/#1595582696232-9e79c2cf-69e9>).

Made in duplicate

One copy given to the patient

One copy kept in the patient's medical file