PNH National Service
LEEDS

UNIVERSITY OF LEEDS

NHS
The Leeds Teaching Hospitals
NHS Trust

The PNH Research Tissue Bank

WITHDRAWAL FORM FOR PATIENTS

Please read this information carefully to find out about withdrawing your consent to use and store samples that you donated to the PNH Research Tissue Bank. If you choose to withdraw, please complete the form overleaf with your details and signature.

You **do not** have to give us a reason for withdrawing.

By filling in the withdrawal form, you are telling us that you no longer wish to participate in the PNH Research Tissue Bank and that wish us to destroy your stored samples so they cannot be used in any further research.

- We will begin acting on your wishes as soon as we have received and processed your withdrawal form.
- You will be contacted to acknowledge your form has been received. If you do not hear from us within 2 weeks of sending your form, please call us on the number below.
- Once your withdrawal has been actioned, the PNH Research Tissue Bank will:
    - Locate and destroy your stored samples or any divided parts of them so they can no longer be used in research projects
    - Delete any research information held about you, apart from a minimum we must keep for audit purposes
    - Write to you once your samples and information have been appropriately destroyed

    However, we will be *unable* to:

    - Remove any data generated from projects which have already used your samples
    - Remove and delete all record of you from our databases. The PNH Team will hold some information (such as your name, date of birth, NHS number etc.) alongside your PNH RTB code to maintain a record of your initial consent to the tissue bank. This information will be subject to strict confidentiality, just as it was when you were active in the tissue bank.

Contact us

If you wish to speak to anyone about the PNH Research Tissue Bank, please contact the PNH Team on **0113 206 8625**.

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If you wish to withdraw from the PNH Research Tissue Bank, please initial the boxes, complete your details and sign your name at the bottom of the form

		Please initial
1	I have read and understood the withdrawal information version 1.1 dated 16/06/2021 for the PNH Research Tissue Bank.	
2	I have previously donated tissue to the PNH Research Tissue Bank and would now like to withdraw my consent for the storage and use of my donated samples.	
3	I confirm that I would like the PNH Research Tissue Bank to destroy my samples and the information collected about me.	
4	I understand that some or all of my samples may have been used in research and that the data generated from this cannot be deleted.	
5	I understand that I need to provide my information in order to allow my samples to be traced, but that this will be treated in confidence.	

Your full name (BLOCK CAPITALS)

Address

Post code

Telephone number

Comments or special requests

Date of Birth

Signature

Date

When completed please return to:

The PNH Team
Haematology
Level 3, Bexley Wing
St James' University Hospital
Beckett Street
Leeds, LS9 7TF