PNH National Service
LEEDS

UNIVERSITY OF LEEDS

NHS
The Leeds Teaching Hospitals
NHS Trust

The PNH Research Tissue Bank

OPT-OUT FROM RECEIVING SIGNIFICANT HEALTH-RELATED RESEARCH FINDINGS

Please read this information carefully to find out about how to opt-out from receiving any further significant health-related research findings that may have implications for you or your family. This form will not withdraw your samples from the PNH Research Tissue Bank – if you wish to withdraw completely, please complete the Withdrawal Form.

If you wish to discuss your decision of opting-out of receiving significant health-related research findings (these are unexpected findings from research using your samples that suggest a serious health condition, or a risk of a serious health condition, which may be important to your healthcare or that of your family), please contact the PNH Team.

If you do decide to opt-out, please complete the form overleaf with your details and signature. You do not have to provide a reason for opting-out.

You should complete this form if

- You ticked the 'yes' box on the PNH Research Tissue Bank consent form to allow for potentially significant health-related findings to be communicated to you *via* the PNH Team

  and

- You no longer wish to receive these or have them discussed with the PNH Team

- We will begin acting on your wishes as soon as we have received and processed your Opt-Out form
- Any significant health-related findings that were found and reported to the PNH Team before you opted out will remain on our databases and will still be accessible to your clinical care team.
- Any significant health-related findings that have not yet been communicated to the PNH Team will not be returned to them or to you.
- Your original consent to join the PNH Research Tissue Bank remains otherwise unaffected by this opt-out.

Contact us

If you wish to speak to anyone about the PNH Research Tissue Bank, please contact the PNH Team on **0113 206 8625 or email pnh.leeds@nhs.net**.

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OPT-OUT FORM FOR SIGNIFICANT HEALTH-RELATED FINDINGS

If you wish to opt-out of receiving significant health-related findings/have them communicated to the PNH Team, 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 Opt-Out information version 1 dated 08/08/2016 for the PNH Research Tissue Bank.	
2	I wish to withdraw my consent to have any significant findings related to my health or that of my family communicated to me *via* the PNH Team.	
3	I understand that by opting-out, I will not receive any future research findings that may be significant for me and that these results will not be shared with the PNH Team.	

Your full name (BLOCK CAPITALS)

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