



# Scientific Advances in Infant Acute Lymphoblastic Leukaemia (SAIL)

## Parent Consent Form

By completing this consent form, you are providing informed consent on behalf of your child to participate in the SAIL database. Please read each statement carefully. If you agree with the consent statements, please confirm so by adding your initials in the corresponding box next to the statement. For your child to participate, you must agree to consent points 1-10. Statements 11 - 13 are optional.

You do not have to agree to optional consent points in order to participate in the database. No matter what you consent to, the healthcare your child receives will never be impacted.

### Required Consent Statements

Please indicate you agree with the statement by initialling the corresponding box.

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| 1 | I confirm that I have read and understood the information in the Parent Information Sheet (version 2, dated 15Jan2025). I have had an opportunity to consider the information, ask questions, and have had these questions answered to my satisfaction.  |  |
| 2 | I agree to regularly input data directly onto the SAIL database relating to my child (known as parent reported outcomes) as described in the Parent Information Sheet.   |  |
| 3 | I agree that my child's health care records, including information stored on centrally held NHS databases and cancer registries, can be accessed by members of the SAIL study team, and copies of clinical data collected as part of my child's standard care can be obtained and stored on the SAIL database.   |  |
| 4 | I agree that copies of data generated from approved research activities conducted on samples collected during my child's routine care can be obtained and stored on the SAIL database.   |  |
| 5 | I understand that I am free to withdraw any data related to my child and/or any personal data related to me from the database at any time, without providing a reason or the medical and legal rights of me and my child being affected.   |  |
| 6 | I understand that data held on the SAIL database may be shared with academic, NHS and commercially-led research groups based in the UK and abroad for use in future cancer and/or other appropriate research, after approval by a data access committee. I understand that any data shared with research groups will be shared in such a manner that it will never be possible to identify me or my child. |  |



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| 7  | I understand and agree that me and my child's donated data will be considered a gift to the University of Oxford. If a commercial product were developed as a result of the research in which my data were used, I would not benefit financially.  |  |
| 8  | I understand that relevant sections of my child's medical notes and data collected by the study may be looked at by authorised individuals from the University of Oxford, NHS organisations and research governance monitors (e.g., to conduct study audits). I allow these individuals to access my research records. |  |
| 9  | I understand that even if I withdraw my child from the database and donating anymore data, it will be impossible to withdraw data already provided to research groups, as data is shared in such a way that identifying my child is not possible.  |  |
| 10 | I voluntarily agree that me and my child can participate in the SAIL Research Database.  |  |

### Optional Consent Statements

Please indicate you agree with the statement by ticking the tick-box. You do not have to agree to the following three statements in order to participate in the study.

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| 11 | I agree to join the SAIL parental consultation group, and am happy to be invited to consultation meetings by the SAIL team via email.  |  |
| 12 | I am happy to be invited to future parent network events hosted by the SAIL team, and am happy to be invited via email.  |  |
| 13 | I agree to be contacted by the University of Oxford regarding participation in future research. I understand that agreeing to be contacted does not oblige me to participate in any further studies. |  |

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| Please write your full name in this box:  |  |
| Please confirm you have completed the consent form by adding your signature in this box:                                  |  |
| Please initial this box if you'd like to join the SAIL study mailing list, and receive regular updates on study progress: |  |



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|-------------------------|--|
| Researcher's signature: |  |
| Date:                   |  |