Researchers' Newsletter

Funded by: CANCER RESEARCH UK for Children & Young People; Blood cancer UK

VIVO BIOBANK NEWSLETTER - CHILDHOOD CANCER AWARENESS MONTH

Welcome to Our Researchers' Newsletter for Childhood Cancer Awareness Month.

In this issue, we highlight how VIVO samples and data are supporting research across children's and young people's cancers. We look back at the **Children's Cancer and Leukaemia Group (CCLG) Annual Conference** in Manchester, where researchers presented work from projects supported by VIVO Biobank. We also showcase two recent VIVO-supported publications in leukaemia and neuroblastoma.

We also take a closer look at the samples available through our **active and legacy trial collections** and highlight some of the **latest projects approved** to use VIVO samples and data, showcasing the variety of research currently being supported through the biobank.

As we continue to develop VIVO as a resource for the research community, we introduce our approach to **FAIR data sharing**, alongside opportunities for **prospective sample collection** and include useful reminders for researchers applying to and working with VIVO biobank.

Thank you to everyone who responded to our recent **researcher survey**, and to those who continue to share publications, research outputs and feedback with us. Your contributions help us continue to develop VIVO to meet the needs of the research community and maximise the research value of donated samples and data.

Inside this issue:

OUR LATEST

Banking Figures

A snapshot of the range of sample types collected in VIVO Biobank since 2022.

Every sample banked with VIVO Biobank has the potential to support new research. If you are interested in accessing samples for your project, please contact us to discuss availability and how VIVO could support your work.

VIVO Biobank Research Highlights

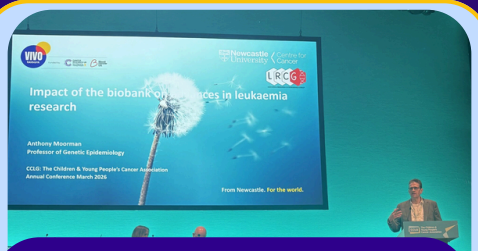
at the CCLG Annual Conference 2026

The Children & Young People's Cancer Association

This year, VIVO Biobank hosted a dedicated Research Highlights Session at the CCLG Annual Conference in Manchester, bringing together researchers, clinicians, charities and patient advocates to showcase research supported by VIVO.

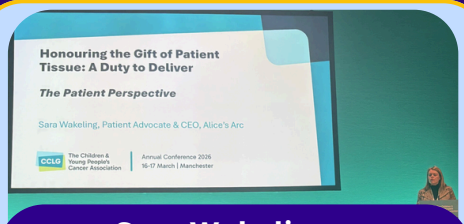
The session highlighted the impact of collaboration across the VIVO network, from patient donation to scientific discovery.

Featured Presentations



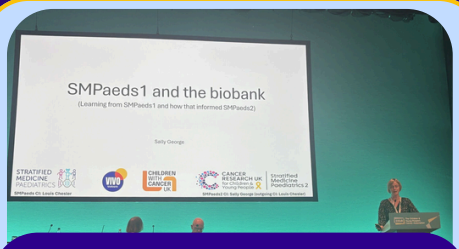
Professor Anthony Moorman
Newcastle University

Showcased how biobanked samples have enabled major advances in childhood leukaemia research



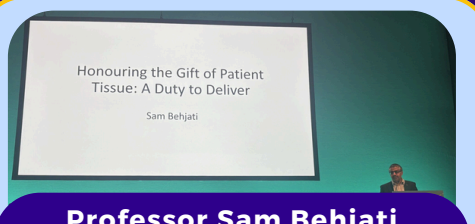
Sara Wakeling
CEO, Alice's Arc

Shared a **parent's perspective** on tissue donation, highlighting the generosity of families and the importance of raising awareness on clinical wards so families have the opportunity to consider biobanking and contribute to future research.



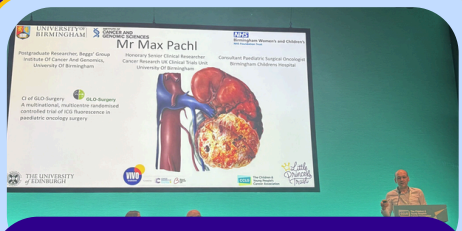
Dr Sally George
Institute of Cancer Research

Highlighted the contribution of VIVO Biobank to the SMPaeds study.



Professor Sam Behjati
Wellcome Sanger Institute

Discussed researchers' responsibility to maximise the value of every donated sample, including **post-mortem donations.** He highlighted how research using these generous donations can advance our understanding of childhood cancer and benefit future patients.



Dr Max Pachl
University of Birmingham

Presented the FRESCO study, using organoid models to better understand Wilms tumour biology

Key Takeaways

Every donated sample has the power to advance childhood cancer research.

Partnerships between patients, families, healthcare professionals and researchers drive meaningful discoveries.

Research supported by VIVO Biobank is improving our understanding of childhood cancers and shaping future treatments.

Biobanked samples are supporting innovative research, from genomic analysis to organoid models, translating patient donations into important scientific advances.

Thank you to all our speakers for sharing their expertise and to everyone who attended the VIVO Research Highlights Session. It was wonderful to celebrate the impact of our collaborative network.

RESEARCH IMPACT

A New Immunotherapy Approach for High-Risk Childhood Leukaemia

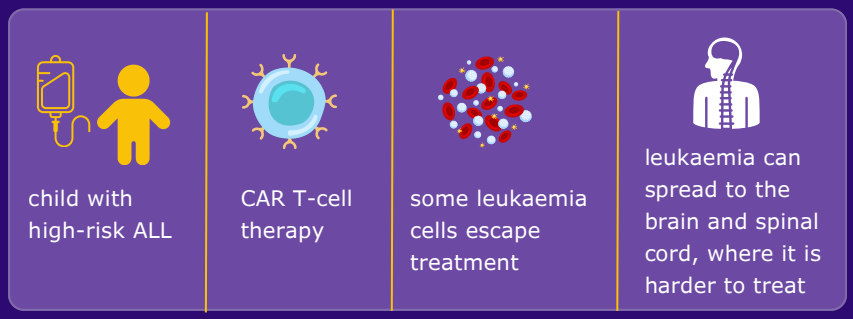
Prof. Anastasios Karadimitris, Prof. Anindita Roy and co-authors

Read the paper
Scan the QR code or click this link to read the full research paper online

VIVO Biobank provided patient samples from children with **acute lymphoblastic leukaemia (ALL)** to support this research into a new dual-target immunotherapy designed to better eliminate aggressive leukaemia and overcome treatment resistance.

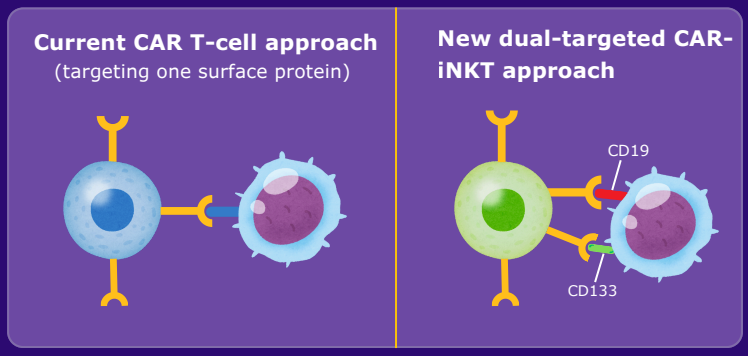
The challenge

Children with a particularly aggressive form of leukaemia (called *KMT2A*-rearranged ALL) are more likely to relapse. In this particular type of ALL, some leukaemia cells can evade current, advanced cell therapies (e.g. CAR T-cell) by changing the proteins on their surface or by spreading to difficult-to-treat areas, such as the brain and spinal cord.



The researchers' approach

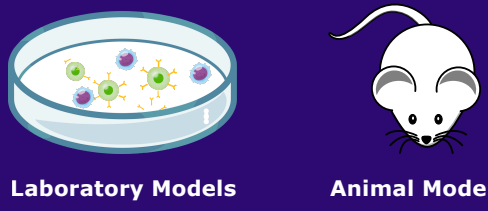
Researchers utilised a new CAR-T-based cell therapy approach, called invariant natural killer T (**iNKT**) cells. These cells were engineered to target 2 surface proteins, **CD19** and **CD133**, found on the surface of leukaemia cells, instead of just one. This makes it more difficult for cancer cells to escape detection and improve treatment effectiveness.



What did the researchers discover?

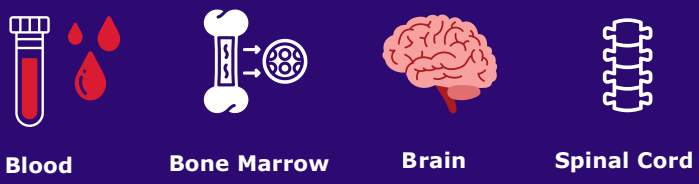
In laboratory studies and animal models, the dual-target CAR-iNKT cell were more effective than current CAR T-cell approaches at eliminating leukaemia.

Effective in preclinical models



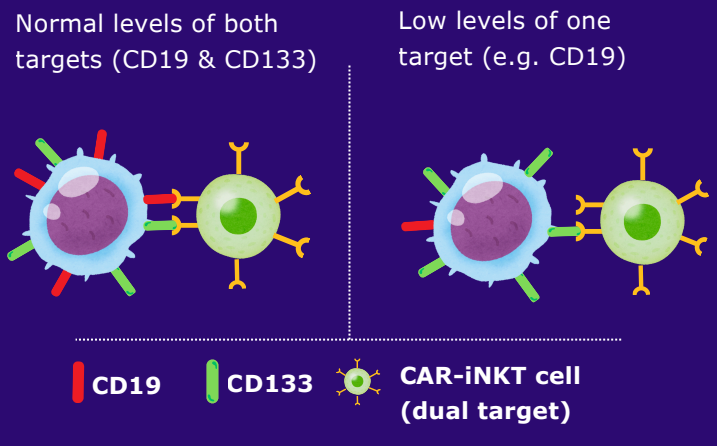
Dual-target CAR-iNKT cells were more effective at eliminating leukaemia cells in both lab models and animal models.

Leukaemia cells eliminated from multiple sites



The treatment successfully eliminated leukaemia from the blood, bone marrow and the tissues surrounding the brain and spinal cord.

Remains effective even when leukaemia cells have lower levels of one target protein



What could this mean for children with cancer?

These findings highlight the potential of dual-target CAR-iNKT therapy as a new treatment strategy for children with high-risk leukaemia. Although the research is still at the preclinical stage and has not yet been tested in patients, it provides strong evidence that targeting cancer in multiple ways could lead to more effective and longer-lasting treatments.

Further research and clinical trials will be needed before this therapy can become part of routine care.

RESEARCH IMPACT

Understanding Which Intermediate-Risk Neuroblastomas May Behave More Aggressively

Prof. Deb Tweddle and co-authors

Read the paper

Scan the QR code or click this link to read the full research paper online

What question were the researchers trying to answer?

Most children with intermediate-risk neuroblastoma have good outcomes with current treatments. However, some children in this group still experience relapse or their disease progresses. The researchers wanted to know whether specific genetic changes in tumours could identify children in this middle-risk whose disease may be more difficult to treat.

How did they investigate this?

The researchers studied **98 tumour samples** from children with this rare form of intermediate-risk neuroblastoma from the UK and 9 countries around Europe. They looked at tumour genetic characteristics, including changes in chromosome structure and specific genes, and compared these findings with how patients had responded over time. They also used more detailed testing in some samples to investigate telomere maintenance and patterns of gene activity.

Tumour Sample | Detect genetic changes | Compare with patients outcomes

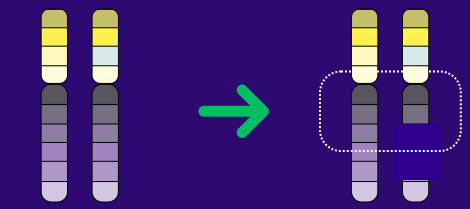
What did the researchers discover?

In this study, researchers found three types of genetic changes in some intermediate-risk neuroblastomas. These changes can make the cancer behave more aggressively and are linked to poorer outcomes.

1) Segmental chromosomal changes

Our cells contain 23 pairs of chromosomes, which carry our genes, the instructions that help control how our cells grow and function.

Segmental chromosomal changes happen when large sections of a chromosome are deleted, doubled and rearranged.

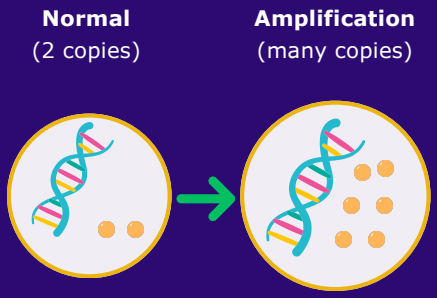


What it means

These large changes can switch important genese on or off, which can make the tumour grow and spread more easily.

2) Oncogene amplification

Oncogenes are genes that drive cell growth. Sometimes cancer cells make too many copies of an oncogene. These leads to the gene being overactive.



What it means

Too many copies act like pressing the accelerator on cell growth, helping the tumour grow faster.

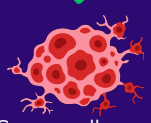
3) p53 pathway alterations

Normal p53 pathway

Protects cells by repairing damage or stopping growth

Altered p53 pathway

Damaged cells continue to grow, increasing the risk of cancer



Cancer cells can grow and survive

The p53 gene is like a "guardian" of the cell. It helps to repair damaged DNA or tells the cell to stop growing if something is wrong.

Alterations in the p53 pathway mean this protection is lost.

What it means

Without this protection, cancer cells can grow and survive when they shouldn't.

What could this mean for children with neuroblastoma?

These findings suggest that looking at specific genetic alterations of a tumour could help better identify children with intermediate-risk neuroblastoma whose tumours may be more likely to behave aggressively. In the future, this information could help doctors and researchers better understand a child's risk categories more precisely and explore alternative treatment options.

Further research and clinical trials are needed before these findings can be used to guide routine treatment.

Legacy & Active Trials hosted by VIVO Biobank

VIVO Biobank holds samples and data from a wide range of childhood cancer trials. These well-characterised patient cohorts, from current and legacy trials, can help generate insights to advance treatments and improve outcomes for children and young people affected by cancer.

Streamlined collection

Provides a single pipeline for streamlined sample collection and removes the need for multiple biobanks.

Supports current clinical trials

Sample repository for many current clinical trials; co-consenting improves access to surplus trial samples.

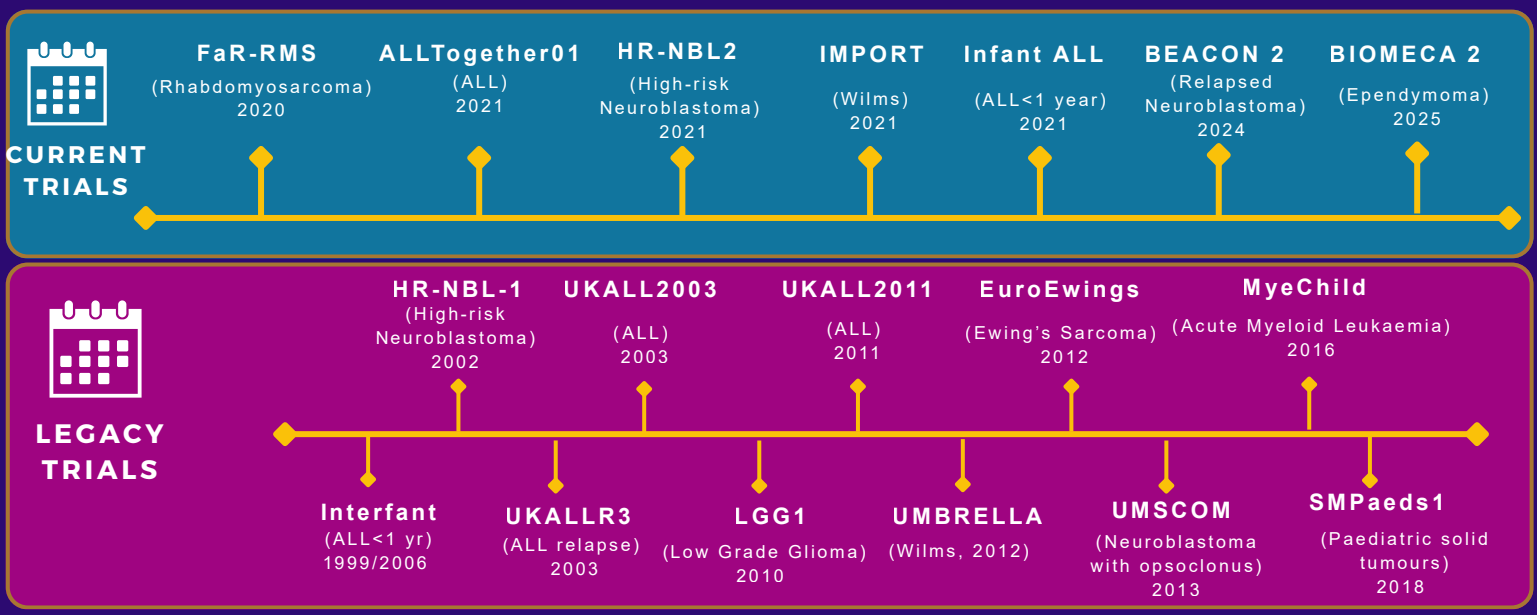
Preserves legacy collections

Holds samples and data from legacy clinical trials, with well-annotated clinical and outcome data.

Enables research worldwide

Range of samples available for high quality research worldwide, inlcuding circulating tumour DNA from liquid biopsy.

VIVO Trials Timeline



A CLOSER LOOK AT OUR CURRENT TRIAL COLLECTIONS

FaR-RMS
Rhabdomyosarcoma : Recruiting since 2020
Phase 2 trial with 1,672 patients enrolled so far.

AllTogether01
Acute Lymphoblastic Leukaemia : Since 2021
Phase 3 trial with 5,138 patients enrolled internationally and 1,276 from the UK.

HRNBL2
High-Risk Neuroblastoma : Since 2021
Phase 3 trial with ~ 800 patients enrolled internationally.

IMPORT
Wilms tumour : Since 2021
Phase 2 international trial.

BEACON 2
Relapsed Neuroblastoma : Since 2024
Phase 2 trial for high-risk relapsed/refractory disease.

BIOMECA 2
Ependymoma : Since 2025
Phase 1 molecular profiling study.

HOW TO ACCESS TRIAL-ASSOCIATED SAMPLES

1) Identify a relevant collection
2) Submit a VIVO application
3) SDAC Review
4) Access approved samples & data

Active trial collections

SDAC review + additional approval by relevant trial investigators is required for ring-fenced trial samples excess to trial requirements.

Legacy trial collections

SDAC review only; additional trial investigator review is not usually required.

All applications are assessed by the VIVO Biobank **Sample and Data Access Committee (SDAC)** to ensure ethical and responsible use of samples and data.

Latest Research Projects Supported by VIVO

VIVO Biobank has approved 8 new research projects and 5 CCLG Pilot Grants in 2026 to date.

2026 AT A GLANCE | **8** Projects approved | **5** CCLG Pilot Grants | **7** Cancer types requested

1 BEACON-BIO: Deep biological characterisation and development of biomarkers for relapsed neuroblastoma

Dr Gudrun Schleiermacher I Institut Curie, Paris
Relapsed and refractory neuroblastoma

Investigating how neuroblastoma evolves from diagnosis to relapse to identify biomarkers of treatment response and resistance, and potential new therapeutic targets.

VIVO Samples/data : Molecular and sequencing data from diagnostic neuroblastoma tumours, with diagnostic plasma.

2 Establishing tumour microenvironment models of paediatric brain tumours

Prof Beth Coyle I University of Nottingham
Medulloblastoma

Developing advanced 3D models of paediatric bran tumours to understand how tumour cells interact with their surrounding environment and identify treatments that target tumour growth while minimising damage to healthy tissue.

VIVO Samples/data : Diagnostic FFPE tumour tissue from Group 3 and Group 4 medulloblastoma cases, with associated clinical information.

3 Identification of spatio-temporal patterns of treatment resistance with spatial biology

Prof Andrea Sottoriva I Human Technopole, Milan
Neuroblastoma

Using **spatial biology** to investigate how neuroblastoma changes between diagnosis and relapse, identifying changers in tumour organisation and its microenvironment that may contribute to **treatment resistance** and **relapse**.

VIVO Samples/data : Matched diagnosis and relapse FFPE neuroblastoma tumour tissue, with associated clinical and sample annotation data.

4 Development of strategies to reduce late effects and improve quality of life for childhood cancer survivors

Dr Gordon Strathdee I Newcastle University
Childhood ALL

Investigating whether reduced-intensity treatment for childhood ALL can lessen treatment-related premature biological ageing, with the longer-term aim of reducing late effects and improving survivors' quality of life.

VIVO Samples/data : Paired constitutional DNA samples from **UKALL2003** patients at week 4 remission and end of treatment, (comparing standard and reduced-intensity treatment groups)

5 Treating Ewing Sarcoma with PRMT5 inhibitors - a novel opportunity with real transaltional potential

Dr Susanne Gatz I University of Birmingham
Ewings Sarcoma

Assessing PRMT5 and related biomarkers in Ewing sarcoma tumours to determine whether PRMT5 inhibitors could be a promising treatment and help identify which patients may be most likely to benefit.

VIVO Samples/data : FFPE tumour tissue from Ewing Sarcoma, rhabdomyosarcoma and osteosarcoma at diagnosis and relapse, with associated clinical and outcome data

6 Investigating the association between host genomic variation and the risk of central nervous system relapse in childhood acute lymphoblastic leukaemia

Prof Christina Halsey I University of Glasgow
Childhood ALL

Investigating whether inherited genetic variation influences the risk of CNS relapse in childhood ALL, with the aim of improving risk prediction and identifying new biological pathways that could inform future treatment.

VIVO Samples/data : Constitional DNA from childhood ALL patients with CNS relapse and matched control groups, with associated clinical, cytogenetic, treatment and outcome data.

7 Scientific Advances in Infant Leukaemia (SAIL Study)

Dr Anindita Roy I University of Oxford
Infant acute lymphoblastic leukaemia

Investigating the molecular diversity of infant ALL by integrating detailed biological and clinical data, with the aim of identifying biomarkers, understanding treatment resistance and supporting more personalised treatment approaches.

VIVO Samples/data : Viable peripheral blood and bone marrow cells collected at diagnosis and defined treatment timepoints, with associated clinical, molecular and outcome data.

8 A Novel Biomarker for the Early Detection of Relapse of Paediatric B-ALL

Prof Joan Boyes I University of Leeds
B-cell acute *lymphoblastic leukaemia*

Investigating a novel biomarker that could help predict relapse in childhood B-ALL, with the aim of identifying high-risk patients earlier and supporting more personalised treatment decisions.

VIVO Samples/data : DNA or viable cells from diagnostic B-ALL samples, linked to relevant clinical, genetic and outcome data from the UKALL2011 and ALLTogether01 trails.

Making VIVO Research Data FAIR

Maximising the value of every donated sample

At VIVO Biobank, we believe the impact of a donated sample can go further when the data generated from our samples are responsibly shared, discoverable and reusable.

What does FAIR mean?

The FAIR principles help ensure that research data are:

F **Findable**: Data can be discovered through established research data repositories.

A **Accessible**: Data can be accessed appropriately, either openly or through controlled access where required.

I **Interoperable**: Data is described and organised so that it can be understood and used across different research platforms and institutions.

R **Reusable:** Data is accompanied by enough information about it's origin, methods and permitted uses to support future research.

Why does this matter?

Connecting VIVO samples, publications and deposited datasets creates a richer research resource.

It allows existing datasets to be discovered and reused, supporting new research questions without unnecessarily using further precious donated material.

The journey from sample to new discoveries

Donated sample
Generously given by patients and families

VIVO-supported research
Samples provided for approved research projects

Research data generated
New datasets created from VIVO samples

Appropriate data repository
Datasets deposited in established repositories (e.g. GEO, Single Cell Portal and others)

Data discovered & reused
Available to the wider research community

More value from every donation
Supporting further translatable discoveries

Your Role in Making VIVO Research Data FAIR

Three simple actions to support data sharing and maximise the value of every sample.

1 Plan

How data generated by your project will be shared.

This includes:

- Dataset type (e.g. genomic, clinical and imaging)
- Methodology and data standards
- Where the data will be deposited

2 Deposit

Resulting datasets in an appropriate, established repository.

Examples of repositories:

- GEO
- European Genome-phenome Archive (EGA)
- Other relevant domain-specific repositories

3 Link

Provide the dataset link back to VIVO by sharing the repository accession or dataset ID, linked to the relevant VIVO sample ID(s) and project ID.

Information we need:

- Repository accession or dataset ID
- VIVO sample IDs & unique sample IDs

Part of the approval process

Your data sharing plan will be discussed as part of the SDAC application, confirmed in your letter of project acceptance and in the material transfer agreement (MTA).

We will not require a copy of your research dataset

Once data have been deposited, we will ask for a simple linkage record containing the Repository accession/ dataset ID and relevant VIVO IDa and unique sample IDs.

VIVO Data Repository Tracker

We are collating information on datasets arising from VIVO-supported research. This will help researchers discover data already deposited in established repositories, and will shortly be available on our website: **vivobiobank.org**

REMINDERS

Key information to support your research with VIVO Biobank

Prospective collections possible

If you are studying a rare cancer type and VIVO Biobank does not currently hold enough of the samples you require, prospective collection may be an option.

Following approval by our Sample and Data Access Committee (SDAC), participating clinical centres can collect and may be able to send samples directly to your research team as newly diagnosed patients become available.

Contact the VIVO Biobank team to discuss whether a prospective collection could support your research → **enquiries@VIVOBiobank.org**

No cost for VIVO samples

Academic Researchers do not pay for samples or associated biobanking costs.

The only cost to the researcher is the shipping of samples from VIVO Biobank to your research institution, all other costs are covered.

More samples for your research, without the added biobankings costs.

Thank you & publication reminder

Thank you to everyone who completed our recent researcher feedback survey and to those who shared publications from VIVO Biobank-supported projects.

Please send a copy or link to any resulting publications to **enquiries@VIVOBiobank.org**, so we can continue to capture and share the impact of research made possible through VIVO

When publishing research supported by VIVO, please acknowledge VIVO Biobank and include the relevant VIVO project ID.

Please quote your project number and the following acknowledgement:

"Samples and data used in this study were provided by VIVO Biobank, supported by Cancer Research UK & Blood Cancer UK (Grant no. CRCPSC-Dec21\100003)"

Don’t overlook PPIE in your application

Patient and Public Involvement and Engagement (PPIE) is an important part of the VIVO application process and is considered by SDAC when reviewing applications.

Please clearly outline how patients and public perspectives are considered throughout your research.

Tell us about both your current and planned PPIE activities.