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Professionals' Newsletter



VIVO BIOBANK NEWSLETTER - CHILDHOOD CANCER AWARENESS MONTH

September marks Childhood Cancer Awareness Month, a time to recognise the progress being made in childhood cancer research and the vital role of healthcare professionals and participating sites in making this possible. Through the continued support of our network, VIVO Biobank is building a national resource of samples and data that enables research across all children's and young people's cancers.

In this edition, we look back at the **Children's Cancer and Leukaemia Group (CCLG) Annual Conference in Manchester**, where researchers shared work supported by VIVO, and highlight recent VIVO-supported publications in leukaemia and neuroblastoma. We also share an overview of **sample registration across our centres**, an update on the growing **TYA biobanking network**, and the latest research and trial updates from VIVO. Alongside these updates, we have included a **sample collection guide** and a number of key reminders to support ongoing banking and sample registration at participating sites.

Thank you to all our research nurses, clinicians, pathology departments and site teams for your continued support. Every patient approached, sample collected and piece of information shared helps strengthen VIVO as a unique resource for research and, ultimately, supports efforts to improve outcomes for children and young people with cancer.

Inside this issue:



CCLG Annual Conference

Highlights and key takeaways from this year's conference.



Recent Publications

New findings in leukaemia and neuroblastoma from VIVO-supported projects.



Sample Registrations Across the UK

An overview of recent sample registrations from our network of sites.



Expanding TYA Centres and Research

Updates on our growing TYA network and opportunities for research.



Trial Updates and Reminders

The latest news from active trials, plus key reminders for sample collection and shipment.



Sample Collection Guide

Practical guidance, flowcharts and tips for sample collection, processing and shipping.



Other Key Reminders

Key information on applications, publications and prospective sample collections.

Update on Processing



Transitioning to Newcastle Biobank for VIVO Biobank sample processing.



VIVO liquid sample processing is moving from UK Biocentre to Newcastle Biobank.

The transition is being introduced in stages, with centres contacted individually.



New address labels will be sent to centres that have not yet transitioned. Once received, please remove UK Biocentre labels and re-label sample boxes as needed.



A **grace period** of three months will apply during the transition, and centres will be given notice before the final deadline.

From UK Biocentre To Newcastle Biobank



For any questions

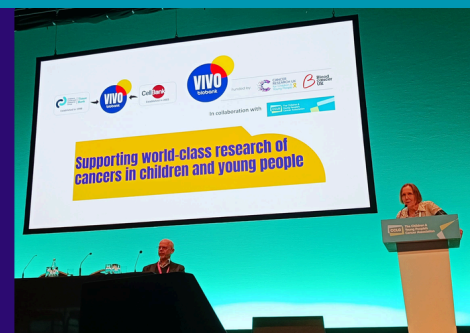
If you have any questions, please do not hesitate to contact us

VIVO Biobank Research Highlights

at the CCLG Annual Conference 2026

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



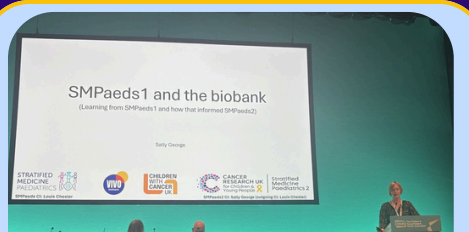
Professor Anthony Moorman
Newcastle University

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



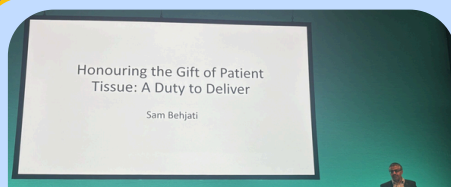
Sara Wakeling
CEO, Alice's Arc

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.



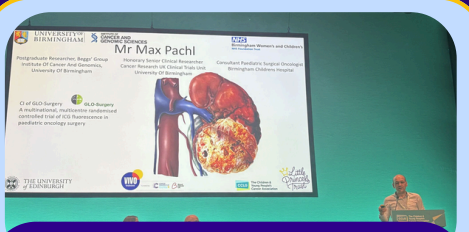
Dr Sally George
Institute of Cancer Research

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, research nurses and site teams who joined our VIVO Research Highlights Session and Biobanking Workshop. We greatly appreciated the opportunity to share expertise, celebrate the impact of our collaborative network and hear your valuable insights.

A New Immunotherapy Approach for High-Risk Childhood Leukaemia

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

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

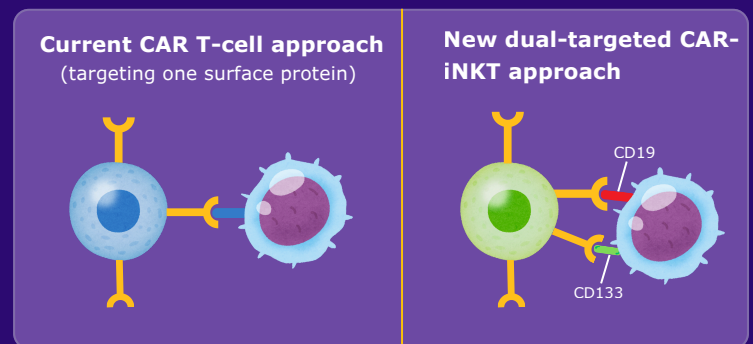
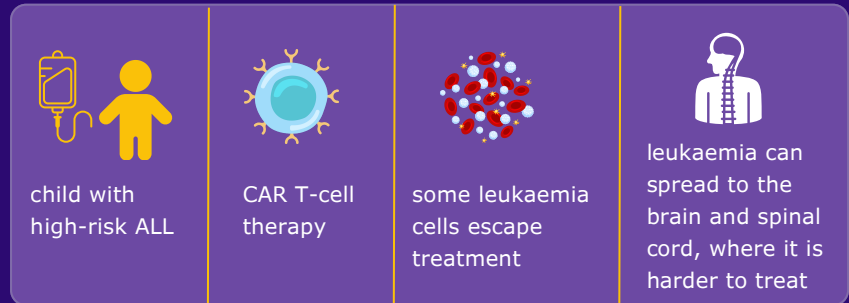
Children with a particularly aggressive form of leukaemia (called *KMT2A*-rearranged ALL) are more likely to relapse. In this particular type of ALL, some leukaemia cells can evade current, advanced cell therapies (e.g. CAR T-cell) by changing the proteins on their surface or by spreading to difficult-to-treat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

The researchers' approach

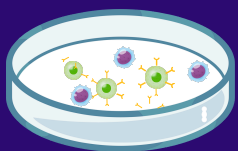
Researchers utilised a new CAR-T-based cell therapy approach, called invariant natural killer T (**iNKT**) cells. These cells were engineered to target 2 surface proteins, **CD19** and **CD133**, found on the surface of leukaemia cells, instead of just one. This makes it more difficult for cancer cells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

What did the researchers discover?

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



Effective in preclinical models



Laboratory Models



Animal 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



Blood



Bone Marrow



Brain



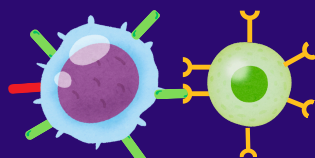
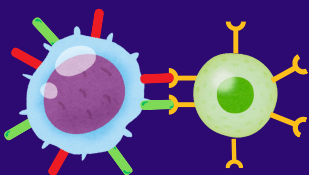
Spinal Cord

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

Normal levels of both targets (CD19 & CD133)

Low levels of one target (e.g. CD19)



CD19

CD133

CAR-iNKT cell
(dual target)

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.

Read the paper

Scan the QR code or click this [link to read the full research paper online](#)



Understanding why some 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 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.



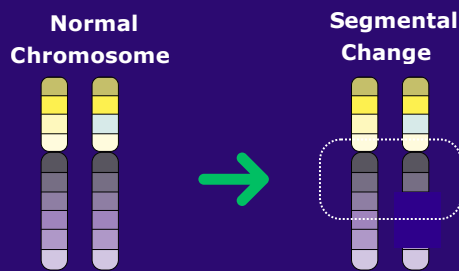
What did the researchers discover?

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 or rearranged.

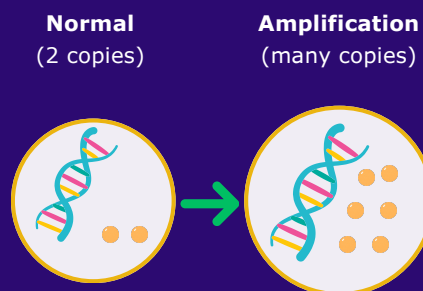


What it means

These chromosomal changes can switch important genes 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. This 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

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.

Altered p53 pathway

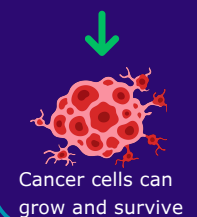


Damaged cells continue to grow, increasing the risk of cancer

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 behave more 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.

Sample Registrations Across the UK

Sept 2025 - Sept 2026

These charts show the number of leukaemia and solid tumour samples registered with VIVO Biobank across clinical centres over the past year.



Every sample donated helps drive research and improve outcomes for children and young people with cancer.

Thank you to all our hospital teams for your continued support.

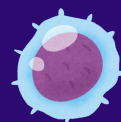


In the last year
(Sept 2025 - Sept 2026)



2,208
Leukaemia
samples

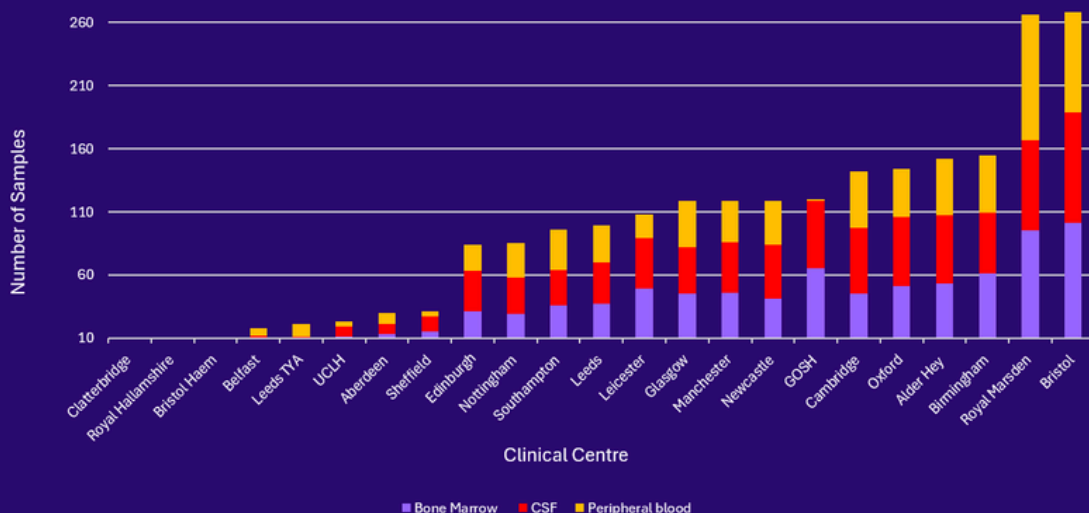
registered across 23
clinical centres



1,717
Solid tumour
samples

registered across 24
clinical centres

Leukaemia sample registrations across sites (Sept 2025-Sept 2026)

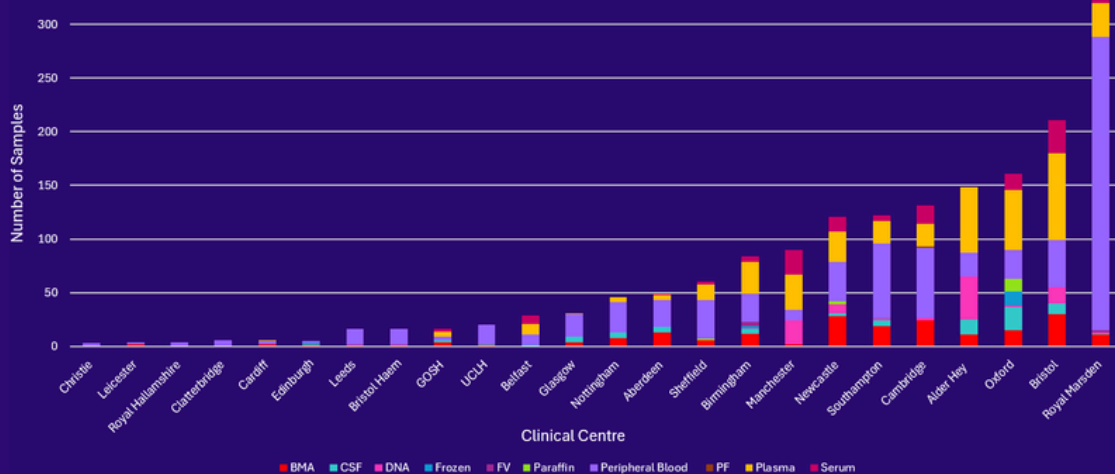


Leukaemia

banking highlights

A big thank you to **Bristol, Royal Marsden, Birmingham, Alder Hey** and **Oxford**, who recorded some of the highest numbers of leukaemia sample registrations over the past year.

Solid tumour sample registrations across sites (Sept 2025 - Sept 2026)



Solid tumour

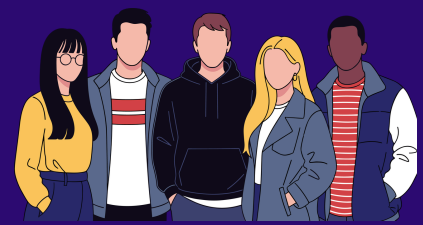
banking highlights

A special thank you to **Royal Marsden, Bristol, Oxford, Alder Hey** and **Cambridge**, who recorded some of the highest numbers of solid tumour sample registrations over the past year.

A heartfelt thank you to all our healthcare professionals who support VIVO Biobank by discussing consent with patients and families, collecting donated samples and associated data, and coordinating their safe transfer to us.

Your continued commitment at every stage makes it possible for VIVO to build a high-quality resource and support vital research into childhood and young people's cancers. We are incredibly grateful for all that you do.

Expanding Opportunities for TYA Cancer Research



VIVO continues to strengthen **Teenage and Young Adult (TYA)** biobanking across the UK, with increasing participation from young people and TYA centres. Our TYA network now includes **11 centres**, and we hope to open all 17 TYA Principal Treatment Centres and their associated designated hospitals.



11
TYA Centres
in our network



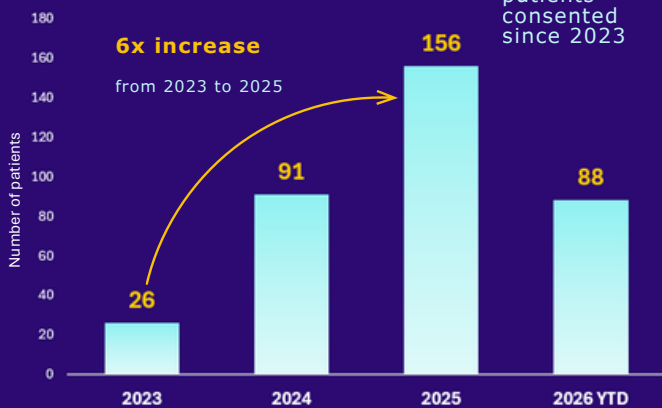
Plan to open
17
TYA Principal
Treatment
Centres

The number of TYA patients consenting and having samples banked has increased substantially since 2023, demonstrating growing engagement across the network. Expanding TYA participation will help ensure more young people can contribute samples and data to support research into TYA cancers.

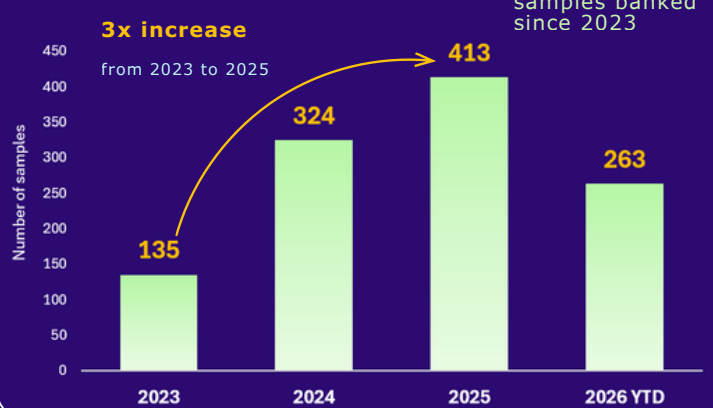


Our aim is to continue to expand the TYA network, so that more young people across the UK can contribute to this national resource.

TYA Patients Consented by Year



TYA Samples Banked by Year



Trial Updates and Reminders

Key information for research teams supporting VIVO Biobank trials.

ALLTogether01 trial

Important for leukaemia patients

Diagnosis bone marrow samples are mandatory samples in the **ALLTogether01** trial but UK banking rates for these samples, are considerably **lower than those of our European colleagues**, despite good overall banking rates.



Bone
marrow
samples at
diagnosis

You do not need to wait for VIVO consent before taking the sample. Our ethics approval allows a **deferred consent period of up to 8 weeks**, so liquid samples can be taken at diagnosis and will not be used for research until consent is obtained.



General Trial Reminders



Co-consent patients

Please remember to co-consent patients to VIVO biobanking alongside trial participation.



Include trial details on the PRF

When registering a patient with VIVO who is enrolled in a trial, please include the **trial name** and **trial number** on the PRF. If they are subsequently enrolled in a trial, please send us these details.



Register trial samples as they are taken

Please send an SRF for each sample collected at every timepoint listed in the trial manual, helping us maintain accurate records and coordinate timely samples transfers to VIVO.

VIVO Sample Collection Guide

A quick guide to collecting, processing and sending samples to VIVO Biobank.

Leukaemia sample collection



Peripheral blood

- 3-5 ml
- Streck tube



Bone Marrow

- 3-5 ml
- ACD tube



Cerebrospinal fluid (CSF)

- 10 drops
- Falcon tube



Send directly to Newcastle Biobank

CSF Transport Reminder

Please make sure Falcon tubes are **securely closed** before transport. If you have experienced leaking tubes, Parafilm can help prevent this.



Need Parafilm?

Contact the VIVO team and we can provide some.

Solid tumour sample collection



Trial Sample?

Is the patient enrolled in a VIVO-supported trial?

→ YES →

Follow the trial manual for sample handling, processing and shipping

→ Transfer periodically to Newcastle biobank

NO

Liquid Samples



Peripheral blood

- 3-5 ml
- Streck tube



Bone Marrow

- 3-5 ml
- ACD tube



Cerebrospinal fluid (CSF)

- 10 drops
- Falcon tube



Send directly to Newcastle Biobank

Frozen/ FFPE tissue



Fresh frozen tissue

- Snap freeze
- Cryovial



Paraffin Embedded Tissue (FFPE)

- Fix in formalin
- Paraffin block



Store on site



Transfer periodically to Newcastle biobank



Samples in High Research Demand

Can you help us increase availability?

We currently have researchers interested in specific **rare tumour types and patient groups**. Please look out for opportunities to consent and bank samples from these patients.



Immature Teratoma

Current research interest in **FFPE tumour tissue**, including samples taken at diagnosis and relapse if where available.



Malignant rhabdoid tumour/ ATRT

We are particularly interested in banking frozen tumour tissue, FFPE, CSF, plasma and blood.



Frozen tissue



FFPE



CSF



Plasma



DNA



Infants and under 2 years

Please remember opportunities to bank samples from **infants and children under 2 years**, where research material can be especially limited.

VIVO Biobank: Key reminders and opportunities

Thank you for helping make every opportunity count for patients and research.



1) Keeping a last wish alive

For families facing the loss of a child or young person to cancer, **post-mortem tissue donation** can be a lasting way to honour their wishes and support future research.

If your team is able to facilitate a post-mortem donation, please remember:



A VIVO Biobank Post-mortem Consent Form must be completed with the family, even if the patient had previously consented to VIVO Biobank during their lifetime.

This is to ensure the post-mortem donation is in keeping with the patient's wishes and the family are comfortable proceeding at this difficult time.



2) A reminder about historic tissue: Samples collected before 1 September 2006

Samples collected and stored before the Human Tissue Act (HTA) came into effect on 1 September 2006 are classed by the HTA as an "existing holding".



Consent under the Human Tissue Act is not required for the storage or research use of these existing holdings.

Please encourage colleagues in Histopathology to consider registering and banking these archival collections - for which we can provide payment.



3) Strong research demand for historic FFPE material



There is strong research demand for historic FFPE samples including those collected decades ago, particularly where samples require off-site storage due to age or space constraints.

- These samples can support a wide range of research analyses.
- Together, we can maximise the scientific value of collections that might otherwise be lost



4) Withdrawing consent or changing consent preferences

Patients and families can withdraw consent from VIVO Biobank or change their preferences at any time.

While initial consent must be in writing, a withdrawal or change of preferences (e.g. not allowing animal research or international sharing) does not have to be in writing.



Please record the reason for declining or withdrawing consent where possible.

Understanding any concerns or barriers to consent helps us improve how we support families in the future.

If a withdrawal or change is expressed verbally:

- 1 Acknowledge and respect the patient/family's decision.
- 2 Complete and sign the Consent Withdrawal Form, including the date consent was withdrawn and by whom.
- 3 Record that the decision was expressed verbally and who communicated it.
- 4 Keep the Withdrawal form with the patient's original consent form in the clinical records.
- 5 Inform the VIVO Biobank team as soon as possible so we can update our database and act promptly.



5) A missed consent form does not mean a missed opportunity

If a consent form was not given in clinic, you can still offer patients and families the opportunity to participate in VIVO Biobank.

- Post the Patient Information Leaflet and Consent Form to the family's home address or email if easier.
- They can return the signed form by post or via email.
- Or they can bring it with them to their next hospital visit.

