

**VIVO Biobank Patient and Public Involvement (PPI) Working Group**

**Type of opportunity:**

To join a group of people (approx. 10-12) affected by childhood, teenage and young adult cancers to provide PPI support and input to the national research Biobank.

**Time commitment:**

2 hours per month on average.

**Payment and expenses:**

This is mostly a home-based role. Travel and food/drink expenses for any in person activity will be covered. An optional payment will be offered for most activities.

**Introduction:**

The VIVO Biobank stores tumour tissue and liquid (e.g. blood, bone marrow) samples from children, teenagers and young adults with cancer and leukaemia. Scientists and clinicians will be able to request these samples to undertake research projects focused on childhood, teenage and young adult (TYA) cancers and leukaemia.

Research helps us to better understand the biology of cancer, and find new and better ways of diagnosing cancer, and finding treatments and cures. Donating samples to the Biobank is voluntary and does not require any additional tests or procedures.

Tissues and liquid samples will be stored at Newcastle University and the UK Biocentre in Milton Keynes. The Biobank will be managed by teams at Newcastle and York Universities. Cancer Research UK (CRUK), Blood Cancer UK (BCUK) and the Children’s Cancer and Leukaemia Group (CCLG) will also oversee the Biobank’s work. Access to tumours for researchers will be given by a committee that include expert scientists, medical doctors and people affected by cancer from this PPI working group.

**The VIVO Biobank will enable researchers to:**

* **Better understand what causes childhood, teenage and young adult cancers**
* **Improve diagnosis of cancer patients**
* **Improve treatments and outcomes for cancer patients**

**Overview of the VIVO Biobank’s PPI Group**

Through their experiences, patients and their families and friends are expert voices on cancer. We want to make sure that we include these voices and experiences in all aspects of the Biobank. We will form a dedicated PPI working group at the Biobank which will:

* Help guide the long-term strategy of the Biobank
* Help develop PPI involvement with the Biobank within the Children and Young People (CYP) cancer community and promote the work of the Biobank to the public
* Provide ideas on how best to design strategies to increase the quantity of samples held at the Biobank, as well as increase research on the stored samples

The working group will be composed of up to 12 people affected by CYP cancer, including patients and their families and friends. This group will include members with experience of a range of cancer types, teenagers and young adults directly affected by cancer, as well as survivors of childhood cancer.

We’re committed to creating an inclusive space to involve all people affected by cancer, irrespective of their race, ethnicity, disability, sexual orientation, gender, age, religion or belief. We actively encourage applications from people of all backgrounds and cultures and believe that a range of views and insight will help us represent all people affected by cancer.

**In this role, you will be involved in one or more of the following:**

* Review patient literature, help with design of patient information sheets and consent forms
* Provide feedback on the design of the Biobank’s website
* Work with members of the Sample Access Committee to provide a patient and family perspective on research applications for samples (NB. no scientific experience needed)
* Help review lay summaries of research results for patients, their families/support network and the public to make sure they are easy to understand
* Help with patient and family education – seek views on information needs, questions, and issues and advise on suitable presentation
* Be a champion for tissue banking across social media and within treatment centres and help increase patient and family awareness in individual centres

# Membership of the PPI working group:

* A chair – elected/ selected from within the group membership
* A deputy chair
* Up to 10 additional members that represent diverse cancer types, geographical location, age and ethnicities
* Biobank manager

Members of CRUK, BCUK and CCLG Patient Involvement Teams may join the group on an ad-hoc basis to support their activities.

# Key Skills and Experience of working group members (who must all be 16+ years old):

* Experience of childhood, teenage or young adult cancer as a patient or as carer/parent/family member/friend
* Are comfortable and willing to share experiences and opinions as someone affected by CYP cancer
* Good communication skills and able to share their thoughts constructively
* Can appreciate the views and needs of a broad range of people affected by CYP cancers beyond your own personal experience
* We expect everyone to work with and respect each other’s experiences and needs

**There is no need to have:**

* Any previous PPI experience
* Any prior knowledge of Biobanking
* An understanding of scientific research

# Time commitment:

# Availability to allocate 2 hours a month on average (on an ad-hoc basis) and respond to consultations within the deadlines set (typically within 2 weeks).

# While virtual meetings will normally be held within the working week, dates and times will be agreed based on the availability of the majority of members

**To support you in your role we will:**

* Provide you with a key contact to answer questions about the role
* Provide timely, clear and easy to understand information about scientific topics to make it easy for you to understand and share your opinions and feedback
* Provide mentoring and group peer support to help you during your role
* Provide IT advice if needed to help you connect to online meetings and help with adhoc training as identified by the patient representative and Biobank Management Team if required to undertake specific aspects of the role

**Additional roles on the Biobank’s Steering and Management Committees for 2-3 members of the PPI working group:**

2-3 members of the PPI working group will also sit on the Biobank’s Steering and Management committees to represent the views and perspectives of patients and their families. These committees are responsible for overseeing the progress, long-term strategy, and day-to-day running of the Biobank.

**Specific roles for PPI members of these committees include:**

* Provide a PPI update from the working group and feedback to the PPI working group about strategic direction
* Advise on strategic direction of the Biobank including
	+ Governance
	+ Communication
	+ Assessment of key performance indicators
	+ PPI strategy and initiatives

# Time commitment of additional committee roles:

# 1 – 4 meetings year

# Most meetings will be held virtually. The Steering Group may meet once a year in person.

# While meetings will normally be held within the working week, dates and times will be agreed based on the availability of the majority of members

**Additional information:**

**Length of role:** 2 years, with an additional 1 year if desired

**Confidentiality:** Some of the information shared may be confidential. Therefore, allrepresentatives will be asked to sign a confidentiality agreement, to treat all information as confidential and not share it with any other individual or organisation

# Travel expenses:

Most activities will be virtual and will not require any travel. Reasonable (standard fares) travel expenses for any in person activities and/or meetings will be covered.

**Payment:**

An optional payment will be offered for most activities. As a guide, £30 will be offered for activities from 20 min – 2 hours, £50 per 2-4 hours and £80 for 4 hours or more.