**Birmingham Cancer Research UK Clinical Trials Unit (CRCTU)**

**Patient Advisory Board**

**Terms of Reference**

***Introduction***

A taskforce was established in November 2020 to develop an ambitious strategy for Patient, Public Involvement and Engagement (PPIE) in cancer research across the University of Birmingham. The taskforce included patients, staff from the Birmingham Cancer Research UK Clinical Trials Unit (CRCTU) and PPIE experts from across the University.

A key recommendation in the strategy is to create a CRCTU Patient Advisory Board, formed of patients from across our key disease areas of research, with the overall aim of providing guidance and input into key CRCTU strategic areas.

Our CRCTU Patient Advisory Board is vital in helping us ensure our research remains relevant and focussed on the patients and public that we serve.

***Remit***

The remit of the CRCTU Patient Advisory Board is to ensure that our work is driven in partnership with patients and the public by providing guidance and input to the CRCTU via our Directors Committee.

The CRCTU Patient Advisory Board will achieve this by:

* Providing advice and guidance on the development and prioritisation of CRCTU’s scientific and operational strategy.
* Co-developing our PPIE strategy, measures of success and workplan.
* Overseeing the training plans for current and future patient contributors.
* Raising issues for discussion with the CRCTU Directors Committee.
* Identifying opportunities for the CRCTU to work with national/regional PPIE initiatives, patient and public groups, signposting and introducting us when possible.
* Advising CRCTU on patient facing publicity and assisting in these activities when appropriate. This may involve some work outside of Board meetings which will be kept to a minimum.
* Acting as a PPIE advocate for the CRCTU.
* Where requested provide a patient view on applications for funding before submission. Giving advice and consideration to clinical trial portfolio reviews, especially for trials that are struggling to recruit enough patients.

As this is a new Board we will work with the Chair and membership to embed and refine our Terms of Reference as and when needed.

***Membership***

Members hold their role for an initial two year term with the potential for renewal for a further year. This allows the Board to bring in new or additional perspectives over time. Additionally, if individual circumstances change, members will be able to step down or abstain for periods as and when needed.

Members of our Board provide a range of perspective of patients, carers and the public. Members of the Board will have lived experience of cancer diagnosis and treatment, either as an individual or by supporting a loved one. We aim to achieve a breadth of experience across our membership that reflects our key cancer types, including paediatric solid and blood cancers, adult lung, brain, colorectal, head and neck, breast and blood cancers. We also aim to achieve a breadth of diversity across our membership to ensure that we are as reflective of our population as possible. We will aim to have between 6-10 members of our Board.

Members may bring their personal and professional experiences to the Board, however should always be clear their role on the Board is as a patient, carer or member of the public.

Members will need to return a signed copy of our Terms of Reference prior to attending their first meeting to ensure that confidentiality of meeting matter is retained.

Members may be asked to give assistance to the CRCTU outside of formal meetings on specific projects and/or activities. This work is entirely optional and will be kept to a minimum to make the best use of time.

***Meetings and decision making***

Meetings will take place bi-annually (twice per year) and will last approximately two hours. Meetings will be held in person at a location within the University of Birmingham but consideration will be given to virtual meetings as and when needed.

Honorariums are offered to members for their time at the standard NIHR rates, including the reimbursement for standard travel to and from meetings.

The Board will have a Chair appointed and this role will be supported in advance and during each meeting by the CRCTU PPIE Leads, the Director of Precision Medicine Trials and Senior Research Nurse. CRCTU administration support will be provided for note taking. Advice provided by the Board is based on consensus, or a majority where a consensus is not reached.

Meetings will be held on the same day and in advance of the CRCTU Directors Committee, with the following typical structure:

* Meeting of the Patient Advisory Board
* Joint lunch with CRCTU Directors Committee
* Joint Patient Advisory Board/Directors Committee

Following the joint meeting of the Patient Advisory Board and CRCTU Directors Committee, the latter will meet to discuss the outputs and next steps.

Member of the Board are encouraged to and have the right to bring items to the agenda prior to the meeting. The members present at the meeting shall be recorded in the minutes and actions.

Some matters discussed with Board members may be considered confidential and these will be made clear before discussion.

The Board will be quorate as long as three patient members are present including the Chair or nominated deputy Chair.

***Confidentiality and non-disclosure of information***

Confidentiality must be maintained in relation to any personal information and information related to personal health that the representative gathers through personal and electronic contact with other PPIE representatives. Any information related to CRCTU Trial activities must be treated in confidence. You can find out more about what we do with your data in our privacy notice at: <https://www.birmingham.ac.uk/crctu>

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