

## Terms of Reference

### Patient & Public Research Panel

### Blood and Transplant Research Unit at UCL

A voluntary group bringing patient & public perspectives to ground-breaking research

#### Background

The Blood and Transplant Research Unit (BTRU) in Stem Cells and Immunotherapies at University College London (UCL), BTRU at UCL in short, is one of four BTRUs funded by the National Institute for Health Research (NIHR). It is an academic partner of NHS Blood and Transplant and supports their need for research to improve the supply of: blood, blood products, stem cells, tissues and organs for transplantation.

The BTRU at UCL and Immunotherapies at UCL looks at:

- Improving haematopoietic stem cell transplantations - the transfer of stem cells which lead to new blood cells in the recipient.
- Immune therapies approaches designed to: replace, repair or strengthen the immune system's response to infection or disease. In order to treat cancers of the blood & lymph nodes and inherited genetic disorders.

#### Purpose of the group

The aim of the group is bringing patient, carer and public perspectives into ongoing research within the unit. The group brings together expertise, experience and an interest in cancer and blood disorders as well as Patient and Public Involvement and Engagement (PPIE) in research. It works with researchers to actively include public involvement and engagement in their research, making the lived experience of patients and carers an essential part of research in the unit and how research is identified, prioritised, designed, conducted and disseminated.

#### Duration of the group

The group's term of office will end on 31<sup>st</sup> March 2022 in accordance with NIHR funding for the BTRU at UCL.

#### Your responsibilities

- Enable and support Patient and Public Involvement and Engagement (PPIE) in BTRU at UCL research projects
- Provide advice and work with BTRU staff on research and planned PPIE activities
- Give feedback on your BTRU involvement experience to drive learning and improvement

#### UCL's responsibilities

- Provide training for new members and as identified by group members
- Be clear about the aims and time commitment of involvement activities
- Foster a supportive environment for meaningful involvement
- Communicate changes made following the group's input, outcomes and impact
- Through our contributions and attitudes, encourage the wider awareness, acceptance, and hence use of external involvement among all BTRU staff

## **Ways of working**

Members will work with BTRU at UCL staff in the following ways, as appropriate to the projects:

- In-person meetings in Central London (currently deferred due to COVID-19)
- Remote meetings via video/voice conferencing, Zoom or similar technologies
- Remote working in the form of feedback on documents either paper or electronically
- Co-creation of documents
- Attending external and internal events

Membership may be terminated if a member becomes non-responsive or fails to engage in tasks for more than six consecutive months.

Members will provide their views on specific research projects and work with BTRU researchers, the PPIE Lead and other panel members to support the implementation and improvement of PPIE processes. This could be in the form of input to funding applications, study materials, co-writing or reviewing summaries of research findings for public consumption, creating and advising on PPIE content and selecting appropriate communication channels and finally, providing feedback on the overall involvement experience.

## **Shared group values**

To provide a safe and welcoming environment for opinions to be expressed, members are asked:

- Be kind and respectful - Provide a non-judgemental environment
- Actively listen and respond to each other with sensitivity
- Keep discussion relevant and concise so all can participate
- Don't stay silent if you don't agree, contribute and be passionate
- Respect everybody's confidentiality, and agree not to discuss, inappropriately, the information provided by and to members

## **Membership**

- The group consists of patients with (blood) cancer and blood disorders, their carers and members of the public
- Insights of patients and public with a specific background or condition outside of the group will be sought as relevant to a research project
- Regular meetings will be hosted by the PPIE Lead to discuss specific research, members' views on PPIE processes and the involvement experience. Where appropriate, researchers, clinicians or others with a specialist contribution may request or be invited to attend.
- Members are free to leave the group at any time for any reason

## Expenses and payment for time

We aim to book travel in advance for attending meetings in-person and you are reimbursed for reasonable out-of-pocket expenses (see specification below). We will offer payment for your time and expenses according to NIHR INVOLVE guidelines:

### 1. Travel costs

- **Public transport** where practical: bus, underground, and trains at standard class or cheaper day rates
- **Own car**, where necessary. While we usually expect you to travel by the most economic method practical, mileage allowance for car users will be **covered** where absolutely necessary at a rate of:
  - 40 pence per mile for the first 50 miles,
  - 23 pence per mile for the rest of the journey
- **Car parking** fees may be claimed where these are unavoidable and where using your own car is necessary (see above).
- **Fines**, parking and speeding fines do not qualify for reimbursement.
- **Taxis** where the circumstances justify the costs incurred
- **Air travel** may also be used where appropriate, if this is cheaper than other forms of transport. You will need to get prior agreement from the BTRU at UCL PPIE Lead
- **Any other transport** arrangements, you will need to obtain prior agreement from the BTRU at UCL PPIE Lead

### 2. Accommodation

We can provide overnight accommodation when it is required. This will be if the meeting takes place over more than one day, or you would have to make an unreasonably early start to get to a meeting, or your journey time makes travel in a day unfeasible.

We can book hotel accommodation for you in advance through an agency. This gives reduced rates and is the usual way we arrange an overnight stay. If you think you will need accommodation, please ask the PPIE Lead to book this for you at least two weeks in advance.

If you wish to book and pay for hotel accommodation when it is required, the BTRU at UCL will reimburse costs for accommodation up to 3-star rating. We are unable to reimburse costs of accommodation with a higher rating, unless this is unavoidable. Our reimbursement limits for 3-star accommodation are:

- £140 per person per night including breakfast and VAT in London
- £90 per person per night including breakfast and VAT elsewhere.

If you choose to stay with a relative or friend, we are not able to offer to cover any of their costs.

### **3. Meals and other refreshments**

For meetings and events, the BTRU at UCL will usually provide meals, snacks and other refreshments. If you need additional refreshments, sometimes referred to as subsistence, these costs will be reimbursed as long as they are reasonable and you provide originals of all receipts. These receipts also need to be itemised, wherever possible. These costs include:

- breakfast where overnight accommodation is required for BTRU at UCL business
- a meal and refreshments when away from home (more than 5 miles) on BTRU at UCL business for more than 3 hours over a recognised meal time (including over meal times while travelling).
- Costs for alcoholic drinks will not be reimbursed.

### **4. Other and office costs**

We try to keep office costs to a minimum by providing any materials required. If you wish to have documents printed and sent in the post, rather than reviewing them online, please let us know and we will provide documents and freepost envelopes to send papers back to us, if needed.

You may make use of home office supplies as part of your involvement with the BTRU at UCL. This might include use of a telephone or internet connection to join meetings remotely, and/or it might include printing out papers at home that have been sent via email.

**When you participate in meetings remotely from your home, we will pay a standing allowance of £5 per meeting** to cover the cost of telephone calls, paper, printing ink and paper, internet connection and other home sundries.

If you need to post any items to us, you may reclaim this cost. This should not include sensitive information, which must be carefully shredded. If, exceptionally, postage amounts to £5 or more you will need to submit a receipt.

BTRU at UCL staff will call you or offer to call you back if you contact them so that you do not incur phone charges. If we ask you to join a teleconference we will provide a dial-in number that will be free to you, provided that you call from a landline and not a mobile phone.

Other expenses are available on request such as carers or alternative carers costs.

We aim to pay your expenses directly or in advance, where possible, rather than reimbursing you at a later date.

## **Payment for time**

Payment for time will be made in the form of gift vouchers as a token of appreciation for contributing your time and expertise at the following rates:

### **1. Meetings, teleconferences and other tasks such as co-writing documents**

- £25 up to 30 minutes (brief task or activity requiring little or no preparation)
- £50 up to 2 hours (with related papers to read in advance)
- £75 per half day (where 2-4 hours is contributed including preparation)
- £150 for a full day (where more than 4 hours is contributed including preparation)

### **2. Document review**

- £25 short documents (brief document, such as a leaflet, information card or other similar)
- £50 documents (including appendices) of no more than 50 pages total
- £80 documents (including appendices) between 51 and 101 pages total

If you are receiving pension payments or benefits, we advise you to seek advice about how payment might affect any pension credits or welfare benefits that you receive before accepting an offer to become involved in paid activities. Staff at your pension centre can tell you how earnings may affect your Pension Credit. Your local authority can tell you how earnings may affect Housing Benefit and Council Tax Support and more information on benefits is available from the NIHR Benefits Advice Service

<https://www.invo.org.uk/benefits-advice-service-for-involvement-for-members-of-the-public/>

Once you have taken advice, please let us know what payment you wish to accept. Our payments policy is flexible, allowing us to offer lesser amounts, or voluntary status, if this is your preference.

## **Privacy Policy and General Data Protection Regulation (GDPR)**

We will protect your personal information, which may be collected if you wish to join the group such as your name, address, email and phone in accordance with UCL's GDPR rules and general privacy policy, which can be found at

<https://www.ucl.ac.uk/legal-services/privacy/general-privacy-policy>

## **Confidentiality**

Panel members shall not release confidential information gained as a result of their involvement with the BTRU at UCL to any external third party without the written approval of the BTRU at UCL PPIE Lead.

## Resources

- For more information about the BTRU at UCL please visit:
  - Website
    - <https://www.ucl.ac.uk/cancer/research/centres-and-networks/nhr-blood-and-transplant-research-unit-stem-cells-and-immunotherapies>
  - Twitter
    - <https://twitter.com/BTRUinStemCells>
- UCL Cancer Institute Expense Payment Form (provided with this document and can be requested from PPIE Lead, see contact details below)

## Contact

**Name:** Linda von Nerée, Patient and Public Involvement and Engagement (PPIE) Lead

**Email:** [l.vonneree@ucl.ac.uk](mailto:l.vonneree@ucl.ac.uk)

**Phone:** 020 3108 7641

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