



Term of Reference and Working Methods

Background

The NIHR Imperial Clinical Research Facility (CRF) is the dedicated clinical research facility for Imperial College Healthcare NHS Trust. There are a wide range of clinical trials taking place at the CRF, looking at new ways of treating many different medical conditions. We are fortunate to have many people taking part in these trials, either because they have the condition under investigation, or as healthy volunteers. However, we would like to not only have people participating in these trials, but also getting involved at other stages of the research cycle.

To do this, we are recruiting a panel of people who are interested in making a difference to clinical research. Members will be invited to take part in a range of activities where they will be asked for their views on different aspects of clinical research, making sure our research is accountable, transparent and relevant to the public. Although the priority of the panel is **patient and public involvement (PPI)**, the panel may also be invited to take part in **patient and public engagement (PPE)** activities (and participation (in research) where relevant).

We use NIHR INVOLVE definitions, namely that **patient and public involvement** is where patients and members of the public are actively involved in the activities, organisation and governance of research projects, while **patient and public engagement** is where information and knowledge about research is provided and disseminated to the public.¹

Aims

The aim of the Patient and Public Involvement Panel (PPI Panel) is to advise the CRF and researchers on how we can improve the way we carry out research by sharing their thoughts and opinions on how clinical trials are run from a lay person's point of view.

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¹ NIHR, 2013, INVOLVE, 2014





Activities

Activities members of the group could be invited to take include:

- Focus groups
- Commenting on research study grant proposals and protocols
- Reviewing patient information sheets and consent forms
- Helping identify research priorities
- Becoming a patient/public voice on a steering committee or advisory group for a study.

Working Methods

When people join the PPI Panel they will be asked a range of questions about whether they are interested in a particular condition as a patient (parent/guardian/carer/family member) or whether they are interested as a healthy volunteer and what types of activities they would like to be involved in.

When we have an activity requiring the help of the PPI Panel, the Patient and Public Involvement Manager will invite people from the Panel to take part. Some activities may only require people with particular conditions, in which case only people who have those conditions will be invited.

We know that different people have different interests and amounts of free time, so many activities will allow you to take part in person or online and you can commit to as much or as little as you like.

Membership

Membership of the PPI Panel is open to:

- People who are willing to contribute their experience of health conditions currently being investigated at the CRF, or in the planning stages.
- Their families and carers
- Healthy volunteers who have already or hope to take part in clinical trials at the CRF.

Person specification

- Must be able to work as part of a team.
- Have a friendly and approachable manner.
- Reliable and trustworthy.





Responsibilities

- During meetings/activities you will be required to offer a patient/carer/public perspective on the development of research, carrying out the research and putting the findings into practice. This is of central importance to the success of this work.
- If required prepare for meetings by reading the associated paperwork

Our responsibilities

- Training when you join the PPI Panel we will ask you about your experience of clinical research and discuss what training and support we can offer. As well as what is expected from you as a PPI panel member.
- Support you will be able to call or email the contact listed below at any time if you have any questions.

Confidentiality

The broad principles of the panel are openness and transparency. However, we aware that members may wish to discuss issues that must remain confidential. When material is circulated or discussed and it is of confidential nature, then it must be stated or marked as 'Confidential'.

All information of a confidential nature must be treated with strict confidence both during the time that a member is involved with the panel as well as after their involvement ends. In line with the Data Protection Act 1998, members must not remove, destroy, share or discuss any confidential information inappropriately unless specifically requested to do so by the ICRF.

The ICRF will keep members' personal information secure and confidential at all times in line with the General Data Protection Regulation (GDPR). Your data will be encrypted and held on a system restricted to just the people that need access to it. You will also have the opportunity to consent to bank details being recorded for fast processing of payments — this is at your discretion. If bank details are recorded, you must sign the attendance sheet when attending all meetings to confirm attendance and confirm you allow us to use your details to process the payments.

For full details of the information we hold, and your rights under GDPR, please refer to our privacy notice on the ICRF website.

Review

We will keep this Terms of Reference and the working practices of the panel under review. You will be notified if the document is amended and asked to confirm your compliance.





Rewards and Recognition

We consider that patients and members of the public who are involved in research should be rewarded and recognised for their contribution. Payment or non-financial reward in recognition of members' time will be based on NIHR Payment guidance for members of the public considering involvement in research (version 1.3, July 2022). All payments are given as appropriate for the activity.

Travel expenses will be covered for meetings and other activities we invite you to attend and we follow involves guidance on payment for involvement.

Payment guidance for members of the public considering involvement in research | NIHR

Claiming travel expenses and payment

The expenses claim form and the non-payroll fees form are both used to process claims. Both will be provided to you. Once finance receives the forms, it takes up to 30 days to process.

• Expenses form (see appendix 1) – used to claim back any travel expenses. Please retain any receipts and submit along with the completed form.

Non-payroll fees form (see appendix 2) – this is used to process any payments to PPI panel members. In the event that travel expenses also need to be claimed alongside this payment, they can also be added to the non-payroll form. All receipts are needed to support this.

For further details please contact:

Aime Boakye - Clinical Project Manager & PPI E Manager

NIHR Imperial CRF, Imperial Centre for Translational and Experimental Medicine, Hammersmith Hospital, W12 0HS

Tel: 020 3313 1312

Email: aime.boakye@nhs.net





Appendix 1 – Expenses Form

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Appendix 2 - Non Payroll Fees Form

Imperial College London

Non-payroll fees NPF Maximum £1000 per annum

This form is not to be used for fee processing relating to Clinical trials. For Clinical trials please use the Clinical Trials payment information (CTPI) form.

This form must only be used to initiate low-value payments of professional fees and similar payments for services rendered by individuals not acting in the course of any employment relationship with the College ("freelance workers"). The College is not required to deduct tax at source from such payments, and the freelance worker is personally responsible for declaring such income on their tax return.

Read the guidance notes at [URL] before using this form. The payee must not already be on Imperial College's payroll (i.e. they must not have received, at any time since April last, a payslip from the Imperial College payroll office).

Examples of the types of payment for which this form may be used:

- guest lecturers whose presentation does not form part of a specified curriculum (eg conference presenters). Up to three lectures per year Visiting musicians, entertainers, actors engaged in communication skills teaching etc.
- royalty payments payable to non-employees;
- volunteers in clinical trials.

Use "Casual payroll" (form Pay 8) for incidental and sporadic payments to casual workers.

Use a purchase order for professional fees exceeding £1000 and all payments to limited companies or partnerships. The supplier's invoice should be processed through Accounts Payable, using a College Order.

When completed and authorised, this form should be sent to Accounts Payable in the Sherfield Building at South Kensington.

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