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NHS
National Institute for
Health Research

NIHR IMPERIAL CLINICAL RESEARCH FACILITY PATIENT AND PUBLIC INVOLVEMENT (PPI) PANEL

INFORMATION PACK

Imperial
Clinical Research Facility

Before we delve into this welcome pack, we wanted to **thank you** for joining us, as a member of our Patient and Public Involvement panel. The ICRF as well as all of the researchers we work with, appreciate the time you will be spending to help support us in our research.

We hope that by working together and matching you with involvement activities we can ensure you find patient and public involvement work rewarding. We have designed this information pack to give you more information about our PPI Panel, how it all works and to outline your role and responsibilities with us.

If there's anything we can help you with, any questions you might have, if you'd like some more training or support, or perhaps if you'd like to get involved with some of our engagement activities let us know and together we can make sure you make the most out of this role!

For further details please contact our Patient and Public Involvement and Engagement Manager:

Aman Nathan

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NIHR Imperial CRF, Imperial Centre for Translational and Experimental Medicine,
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NIHR Imperial Clinical Research Facility (ICRF)

The ICRF is a purpose built environment, which is essential in supporting many experimental medicine studies i.e. investigations in humans to identify the cause of disease and/or to test the validity and importance of new discoveries and treatments. Whilst we are able to help design and support the studies, the CRF is also staffed with experienced medical teams including Good Clinical Practice trained research nurses and physicians who conduct the research visits and collect samples and operational staff fully trained in research governance and regulatory affairs.

The ICRF provides comfortable clinical accommodation for healthy volunteers and patients taking part in studies requiring long-term in-house monitoring as well as facilities for day case visits.

Terms of Reference

1. Background

We are fortunate to have many people taking part in our 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.

The ICRF wishes to make sure that the patient and public voice impacts our research strategies, projects and functions, making sure our research is accountable, transparent and relevant to the public. Therefore, we want a panel, of patients and members of the public to help us identify, plan and design our research within these themes. 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]

Involve is a national advisory group funded by the National Institute for health research, which provides expertise and support in the field of public involvement in research. For further information please visit the website: http://www.invo.org.uk/

2. Aims

The ICRF Patient and Public Involvement Panel aims to:

- Support the governance of patient and public involvement and engagement approaches and activities within the ICRF
- Identify and prioritise topics for research
- Design and comment on research plans, protocols and materials

[1] NIHR, 2013, INVOLVE, 2014

- Identify and facilitate ways that patients/members of the public are involved in research including recruitment of participants to clinical studies
- Disseminate research results
- Support researchers to assess the impact of PPI in their work

3. Membership

Membership of the ICRF is open to those who are both directly or indirectly affected by, or interested in, our research areas. Members will include patients and members of the public (both with and without previous experience of PPI) to make sure that the ICRF benefits from varied skills, expertise and experience.

Membership of this Panel is voluntary but requires members to be committed to attending the minimum amount of meetings. Alongside meetings you may be sent a range of opportunities, it is up to you which you choose to respond to. When members are unable to attend meetings, contributions to the areas to be discussed are expected via e-mail or post.

The Panel may choose to invite other patients/members of the public involved with the ICRF, other universities and/or representatives of voluntary or community organisations on a one/off or long term basis. In addition, they may also invite those with responsibility for **public engagement** within their organisations or research teams or those academics/scientists/researchers/practitioners with **patient and public involvement/public engagement** interest or activities may be invited on a one/off or long term basis. Observers, guests and presenters may also be invited on a one/off basis. Other research bodies e.g.[*Medical Research Council (MRC)]* and their representatives may be also invited.

All members will undergo an induction process in the Imperial Clinical Research Facility, which will include a tour of the facility and an introduction into Patient and Public Involvement.

4. Meetings

The Panel intends to meet at least 3 times a year for 2 hours. Longer or more frequent meetings may be agreed to discuss certain actions and priorities.

The meetings will be co-chaired by a *'professional'* and a '*lay*' chair. The *'professional' chair is Aman Nathan* and the *'lay'* chair is to be decided and can be rotated at each meeting. The lay chair is a voluntary position and is not expected to take on any other responsibility apart from chairing the meeting together with the professional chair on the day of the meeting. [*Having both a Lay Chair as well as a Professional Chair is good practice for the purpose of equilibrium although there may be some situations where this is not appropriate/possible*]
Meeting dates will be circulated in advance. A minimum of four lay members of the panel must be required for a meeting, not including the lay chair.
We know that different people have different interests therefore subgroups have been created to work with specific projects and/or do specific actions. Members of a subgroup may communicate face-to-face or by email at agreed times between the meetings of the panel.
The panel members may be sent research material, such as research proposals and protocols, research participant material, electronically or by post to review and comment on between panel meetings. Members will be informed of the amount they will be rewarded for such tasks and can choose whether they wish to take part or not. The best way to communicate with members of the panel will be agreed with each person.

5. 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. On these occasions, the meetings may have two parts, one for non-confidential matters and another one for confidential matters. Guests or non-members will be excluded from the confidential parts of the meetings.
When material is circulated or discussed and it is of confidential nature, then it must be stated or marked as *'Confidential'* or as '*Strictly 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. 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.

In the case of members not attending the minimum amount of meetings, personal details will be kept for a year and then will be removed from our system or will be removed upon request.

6. Accountability and Responsibilities

This is a voluntary panel and members are accountable to each other for the aims of the panel. There may also be accountability to the ICRF for specific tasks.

The main responsibilities of the panel members are linked with its aims and objectives and will be set out in a separate "Role Description" document. In addition, members will monitor and review the panel's progress and show mutual respect to each other.

7. 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.

8. 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 INVOLVE's Policy on payment of fees and expenses for members of the public actively involved with INVOLVE (February 2016). All payments are given as appropriate for the activity.

Travel expenses will be reimbursed in accordance with this policy together with other expenses and costs.

9. 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.

1) Expenses form (see appendix 1) – used to claim back any travel expenses. Please retain any receipts and submit along with the completed form.
2) Non-payroll fees form (see appendix 2) – this is used to process any payments to PPI panel member's. 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.

Role Description for PPI Panel Member

1. Background

The aim of the ICRF Patient and Public Involvement Panel (PPI Panel]) is to increase the quality of our research to ensure the views of those it affects are taken into account and that it is relevant to the public. The PPI *Panel* will assist, support and advise researchers and act as a 'critical friend' on how best we can improve research strategy and projects.

2. Your responsibilities:

A. Attend at least 3 meetings per year, lasting for approximately 2 hours. Attendance at meetings is voluntary but requires members to be committed to the minimum amount.
B. During meetings/activities you will be required to offer a patient/carer/public perspective on things such as: development of research; ways of carrying out the research; and putting the research findings into practice.
C. If you cannot attend a meeting, you are expected to notify the ICRF.
D. To maintain positive interactions between meetings - You may be asked to complete activities or provide advice via email/by post between meetings. It is up to you which activities you chose to partake in.
E. To contact us between meetings if required.
F. If required, prepare for meetings by reading any paperwork provided to you in advance.
G. Keep confidential any information which you are asked to or which is marked as "Confidential".
H. To agree to the Terms of Reference with the other Panel members which you will follow.
I. Examples of tasks which you may be asked to do are as follows:
   - **Commenting/advising** on PPI plans in research projects or suggesting PPI plans where there are none.
   - **Designing and commenting** on research materials such as drafts, research protocols, research funding applications, questionnaires, patient information sheets and consent forms including the use of lay language.
   - **Identifying and facilitating ways** that patients/members of the public are involved in research e.g. developing research tools and information, gathering and reviewing documentary evidence, analysing and interpreting the results of research.
   - **Disseminating**, i.e. in other organisations or networks, writing progress reports or newsletters, lay summaries of research results, giving public talks, presenting at conferences and events, being a co-author on a journal article or newsletters.

- **Supporting researchers** to evaluate the impact of patient and public involvement, i.e. recording short and long term impacts from your perspective, supporting the establishment of monitoring and evaluation PPI and PE mechanisms in research.
- **Advising on ways to recruit** patients and members of the public to take part in clinical trials as participants.

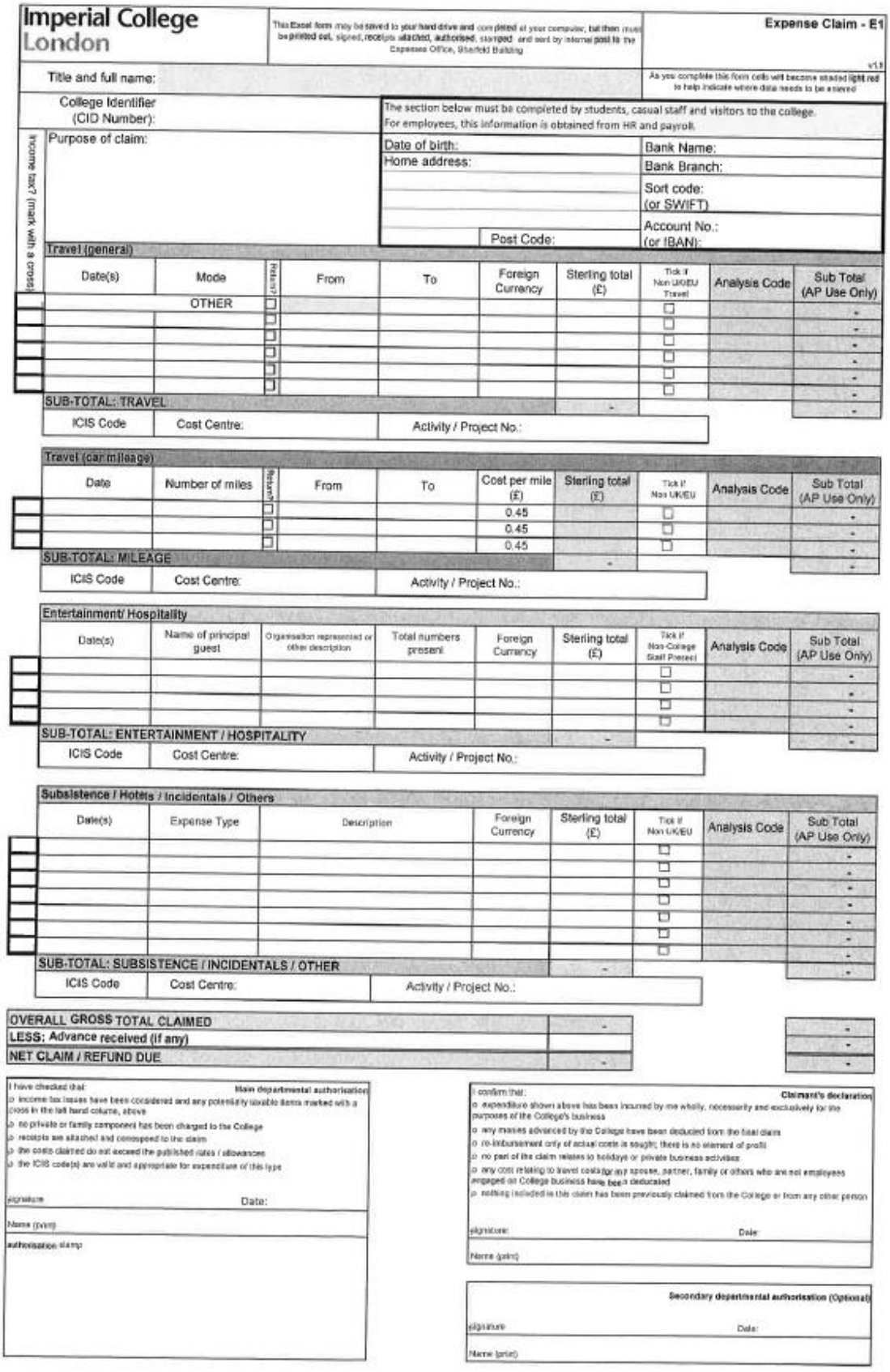
3. Person specification

- Be able to work as part of a team.
- Have a friendly and approachable manner.
- Be reliable and trustworthy.
- Respect others' views.
- Have good communication skills.
- Be honest and have integrity.
- Be comfortable speaking in front of others.
- IT skills (preferable) – using email, managing meeting papers, reviewing and commenting on documents online. However, if a [*Group/Panel*] member does not have these skills, it is possible that other arrangements can be made for communication and dissemination of papers.

4. Our responsibilities

A. To provide training – when you join the PPI panel we will ask you about your experience of research and discuss what training and support we can offer you.
B. To provide support – you will be able to call or email the PPI manager, Aman Nathan, if you have any questions.
C. To keep you updated with the research happening in our team, you may be invited to attend ICRF events.
D. To send you (by the method you request) meeting agendas and any required reading for a panel meeting at least one week in advance.
E. To process your expense claims and reward you for your time within a reasonable time.
F. To provide regular feedback on the changes made as a result of the panel feedback.

Appendix 1 – Expenses Form



Imperial College London

This Excel form may be saved to your hard drive and completed at your computer, but then must be printed out, signed, receipts attached, authorised, stamped and sent by internal post to the Expenses Office, Sherfield Building

Expense Claim - E1

v1.1

Title and full name:

As you complete this form cells will become shaded light red to help indicate where data needs to be entered

College Identifier (CID Number):

The section below must be completed by students, casual staff and visitors to the college. For employees, this information is obtained from HR and payroll.

Purpose of claim:

Date of birth:

Home address:

Post Code:

Bank Name:

Bank Branch:

Sort code: (or SWIFT)

Account No.: (or IBAN):

Income tax? (mark with a cross)

Travel (general)

Date(s)	Mode	Return?	From	To	Foreign Currency	Sterling total (£)	Tick if Non UK/EU Travel	Analysis Code	Sub Total (AP Use Only)
	OTHER	☐					☐		-
		☐					☐		-
		☐					☐		-
		☐					☐		-
		☐					☐		-
		☐					☐		-
SUB-TOTAL: TRAVEL						-			-

ICIS Code | Cost Centre: | Activity / Project No.:

Travel (car mileage)

Date	Number of miles	Return?	From	To	Cost per mile (£)	Sterling total (£)	Tick if Non UK/EU	Analysis Code	Sub Total (AP Use Only)
		☐			0.45		☐		-
		☐			0.45		☐		-
		☐			0.45		☐		-
SUB-TOTAL: MILEAGE						-			-

ICIS Code | Cost Centre: | Activity / Project No.:

Entertainment/ Hospitality

Date(s)	Name of principal guest	Organisation represented or other description	Total numbers present	Foreign Currency	Sterling total (£)	Tick if Non-College Staff Present	Analysis Code	Sub Total (AP Use Only)
						☐		-
						☐		-
						☐		-
						☐		-
SUB-TOTAL: ENTERTAINMENT / HOSPITALITY					-			-

ICIS Code | Cost Centre: | Activity / Project No.:

Subsistence / Hotels / Incidentals / Others

Date(s)	Expense Type	Description	Foreign Currency	Sterling total (£)	Tick if Non UK/EU	Analysis Code	Sub Total (AP Use Only)
					☐		-
					☐		-
					☐		-
					☐		-
					☐		-
					☐		-
					☐		-
SUB-TOTAL: SUBSISTENCE / INCIDENTALS / OTHER				-			-

ICIS Code | Cost Centre: | Activity / Project No.:

OVERALL GROSS TOTAL CLAIMED	-	-
LESS: Advance received (if any)		-
NET CLAIM / REFUND DUE	-	-

I have checked that: **Main departmental authorisation**

- income tax issues have been considered and any potentially taxable items marked with a cross in the left hand column, above
- no private or family component has been charged to the College
- receipts are attached and correspond to the claim
- the costs claimed do not exceed the published rates / allowances
- the ICIS code(s) are valid and appropriate for expenditure of this type

signature Date:

Name (print)

authorisation stamp

I confirm that: **Claimant's declaration**

- expenditure shown above has been incurred by me wholly, necessarily and exclusively for the purposes of the College's business
- any monies advanced by the College have been deducted from the total claim
- re-imbursement only of actual costs is sought; there is no element of profit
- no part of the claim relates to holidays or private business activities
- any cost relating to travel costs for any spouse, partner, family or others who are not employees engaged on College business have been deducted
- nothing included in this claim has been previously claimed from the College or from any other person

signature: Date:

Name (print)

Secondary departmental authorisation (Optional)

signature Date:

Name (print)

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.

Section A: Personal Details			College identifier (CID) if known	0	0						
Title		Surname or Family name									
First Names		Former Surname (if applicable)									
Date of Birth		Gender	Male ☐	Female ☐							
Residential Address											
First line of address		Town									
County		Postcode									
Telephone number		Mobile									
Bank Details											
Name of Bank		Sort Code									
Account number (8 digits)		IBAN or Swift code for international payments									

Section B: Services provided

Department or unit in College	**Give a brief description of the work undertaken**

Section C: Cost and charging instructions				
	Cost centre	Activity or project	Analysis code	**Amount**
Fee payable, excluding VAT				£
VAT if applicable				
Travel or other expenses				£

***Section G: Freelance* Worker's declaration**	***Section H*: Departmental authorisation**	
I declare that: • I have provided the services set out hereon as a freelance worker, and am not (nor have been at any time in the current tax year) an employee of Imperial College. • all personal details completed above are correct	*STAMP HERE*	
Signed	**Signed**	**Signed**
Date	**First Departmental Officer's name and department (print)**	**Second Departmental Officer's name and department (print)**