**[*INSERT RESEARCH TEAM NAME*] Patient and Public Involvement (PPI) [*Group/Panel*] –**

**Terms of Reference**

**1. Background**

The [insert research group/team name] at Imperial College London (ICL) is a [*insert some background information about the team* *eg. government funded research partnership between* [*insert partners if any]*] *(see Appendix 1 – [insert research group/team name] Organogram (if any))*. The [*insert research group/team name]* conducts research across the following themes:

* **[insert theme]**– [*insert brief explanation of theme here in plain English*]
* **[insert theme]**– [*insert brief explanation of theme here in plain English*]
* **[insert theme]**– [*insert brief explanation of theme here in plain English*]

The [*insert research group/team name*] 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 [*Group/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 [*Group/Panel*] is ***patient and public involvement (PPI)***, the [*Group/Panel*] may also be invited to take part in ***public engagement (PE)*** 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 **public** **engagement** is where information and knowledge about research is provided and disseminated to the public.[[1]](#footnote-1)

**2. Aims**

The *[insert research group/team name*] Patient and Public Involvement *[Group/Panel*] (PPI Group/Panel) aims to:

* Support the governance of patient and public involvement and engagement approaches and activities within the [insert research group/team name]
* Identify and prioritise topicsfor research
* Design and comment on research plans, protocols and materials
* 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 [*Group/Panel*] is open to those who are both directly or indirectly affected by, or interested in, our research areas. Members will include patientsand members of the public (both with and without previous experience of PPI) to make sure that the [*Group/Panel*] benefits from varied skills, expertise and experience. [*This paragraph may need to be amended if your group/panel comprises patients/carers with specific lived experience of a condition*]

All potential members of the [*Group/Panel*] will be asked to complete a form about their background and their PPI experience *(Appendix 2 - PPI Background Information Form [this form will need to be adapted so that is suitable for your project/potential members]*).

Membership of this [*Group/Panel*] is voluntary but requires members to be committed to attending meetings and respond to emails/correspondence. The initial term of membership is for [*insert period of time*] from [*insert date*]. When members are unable to attend meetings, contributions to the areas to be discussed are expected via e-mail or post.

New members may be recruited to the [*Group/Panel*] if there are gaps in experience/knowledge/capacity of [*Group/Panel*] members.

The [*Group/Panel*] may choose to invite other patients/members of the public involved with [*insert research group/team name*]; 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.

**4. Meetings**

The [*Group/Panel*] intends to meet approximately [*insert number –bear in mind that regular meetings keeps members engaged committed and interested*] times a year for [*insert number*] 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 [insert name of research team member/s]* and the *‘lay’* chair is to be decided and can be rotated at each meeting. The lay chair 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 [*Group/Panel*] is required for a meeting.

[We know that different people have different interests therefore subgroups may be 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 [*Group/Panel*].[*You may choose not to include this paragraph].*

The [*Group/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 [*Group/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 [*Group/Panel*] will be agreed with each person. [*Bear in mind that some people may not use email*].

**5. Confidentiality**

The broad principles of the [*Group/Panel*] are openness and transparency. However, the [*Group/Panel*] is aware that members may wish to discuss issues that will 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 [*Group/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 [*insert research group/team name*].

[*insert research group/team name*] will keep members’ personal information secure and confidential at all times. [*Insert appropriate wording relating to how this information will be stored/used eg. Your data will be encrypted and held on a system restricted to just the people that need access to it – check with your Data Protection Co-Ordinator*].

**6. Accountability and Responsibilities**

This is a voluntary [*Group/Panel*] and members are accountable to each other for the aims of the [*Group/Panel*]. There may also be accountability to the [*insert research group/team name*] for specific tasks.

The main responsibilities of the [*Group/Panel*] members are linked with its aims and objectives and will be set out in a separate “Role Description” document (Appendix 3 - Role Description). In addition, members will monitor and review the [*Group/Panel’s*] progress and show mutual respect to each other.

**7. Review**

This Terms of Reference and the working practices of the [*Group/Panel*] will be reviewed at the end of the [*insert time period*].

**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) (*Appendix 4 –* INVOLVE’s Policy on payment of fees and expenses for members of the public actively involved with INVOLVE).

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

***Appendix 1 -*** [*insert research group/team name*] *Organogram*

***Appendix 2 -*** *PPI Background Information Form*

***Appendix 3-*** Role Description

***Appendix 4*** *–* INVOLVE’s Policy on payment of fees and expenses for members of the public actively involved with INVOLVE

1. NIHR, 2013, INVOLVE, 2014 [↑](#footnote-ref-1)