# Processes of Care for Persistent Critical Illness Steering Group: Terms of reference

This document sets out the Terms of Reference for the Steering Group of the Processes of Care for Persistent Critical Illness Project. The Steering Group coordinates the project and organises its activities.

The Steering Group will include representatives of patients, carers and clinicians representing the ICU interprofessional team.  These may be members of a charity or professional organisation within the project area.  Members will bring with them knowledge of the condition, and an understanding of the patient, carer and clinician perspectives.  Members will need to be fully engaged in the Steering Group processes and have the time to carry out their role. The group aims to providing a forum for discussion of progress, to ensure the project progresses in the target timeframe.

## Membership of the Steering Group

The Steering Group membership must be a balance of patients, carers and clinicians representing the ICU interprofessional team. The group is open to former patients who have experienced an ICU stay of over 7 days, family members or carers of these patients, and ICU clinicians, and the research team, and is planned that 10 members will participate in addition to the Chair with a minimum of 3 patients/family members.

It is agreed that a quorum of 2 members of the research team (including L Allum present as Chair), 2 patient/carer representatives and 3 healthcare professionals will need to be present for Steering Group meetings to go ahead and for decisions to be made.

## Role of Steering Group members

Steering Group members are asked to contribute, as a minimum, their expertise and their time, and to be prepared to approach their established contacts and networks to aid with recruitment to the study. All Steering Group members are asked to commit to working according to the following principles:

* Inclusivity: working with other members respectfully and constructively and ensuring the full range of patient, carer and clinical stakeholders are involved in the project processes
* Equality: patients, carers and clinicians, and the knowledge and experience they bring, are of equal value to the project
* Fairness and transparency: declaring any personals interests, and ensuring decisions and activities are documented openly
* Evidence based: ensuring the work of the project recognises the existing knowledge base for persistent critical illness.

We aim to have a diverse membership, including representation of a range of professions within ICU, and a lay panel varied in experience with research. We will therefore select members according to this aim.

Members of the Steering Group will need to agree the resources (including time and expertise) that they will contribute to ensure that each stage of the process is completed.  Members of the Steering Group will:

* Champion the project to potential partners.
* Aid recruitment to the study, by advising on recruitment methods to ensure a wide and representative group of patients, carers, and clinicians and emailing personal and professional contacts to invite participation
* Take part in 2-3 Steering Group meetings/teleconferences a year to maintain project momentum
* Review study documents (such as the Delphi survey and participant communication) to ensure they are understandable and accurate.
* If unable to attend, submit comments when able. Where a Steering Group member is unable to attend a meeting, decisions made at the meeting will be respected
* Respond within 2 weeks with feedback on project materials
* Have oversight of the items included in the Delphi online surveys
* Agree the final shortlist of items to be taken to the final consensus-building workshop, and help to publicise it
* Help publicise the findings of the project

## Declaring interests and Confidentiality

* Steering Group members are asked to declare any interests relevant to the Processes of Care for Persistent Critical Illness project, for example: authorship on related studies; or financial earnings from tools, technologies or drugs related to the clinical area. Relevant interests may be professional, personal or related to an interest in or involvement in clinical research. Members will be provided with a declaration form, adapted from the James Lind Alliance, and the interests of each member will be shared among the group. This is to encourage a culture of openness and transparency. The same form asks Steering Group members to consider their agreement to being named in publicity about the project.
* Documents will be sent by email; all documents are confidential and should not be shared outside the Steering Group without discussion with the Study Team.

## Timescales

* The first Steering Group meeting will be in November 2019 [exact date TBA]. We propose that the final meeting will take place in October 2024. We hope that members will maintain their involvement to aid with consistency in the study, but members can end their involvement at any time if they wish.
* The Group will meet three times a year in central London, and members can participate through online meeting software (Zoom) if unable to attend in person.
* Members of the Group will receive papers one week before each meeting, including an Agenda, sent by Laura Allum.
* Meetings will be audiorecorded to allow minutes of the meeting to be accurately recorded, and will be kept by Laura Allum, and circulated to all who attended the meeting within a week of the meeting taking place.

## Lay members

* Lay members will have access to a free one-day training course at Guy’s and St. Thomas’ Biomedical Research Centre, <http://www.guysandstthomasbrc.nihr.ac.uk/patients-public/training-for-patients-and-members-of-the-public/> to support understanding of their role in research
* Laura Allum will meet with lay members via online meeting software (Zoom) in the week before Steering Committee meetings to brief them on plans and allow time for questions.
* Lay members will be paid for their time at £150 per day, £75 per half day, and £50 per teleconference meeting of approximately an hour with papers to read in advance. Travel costs will be reimbursed, and we will provide a claim form.

## Contact details:

If you are interested in participating in this steering group please contact Laura Allum (laura.allum@kcl.ac.uk) by 31st March 2020.