



## **Northern Ireland Cerebral Palsy Register (NICPR) Public Involvement Group Terms of Reference and membership**

### **The Role of the Group**

- (i) To advise on engagement and public involvement (PI) of persons living with Cerebral Palsy (CP), their families and friends.
- (ii) To help guide the direction of NICPR research.

### **Responsibilities of the Group**

- (i) To provide advice and guidance as appropriate to NICPR regarding their approach to PI.
- (ii) To develop appropriate documents and resources to support the development of the NICPR. Resources will be available in plain language and a variety of formats to suit different audiences and abilities.
- (iii) To ensure the NICPR upholds best practice standards in relation to patient and public involvement.
- (iv) To develop and demonstrate (a) the impact of the NICPR and (b) the impact of public involvement on the NICPR.
- (v) To make recommendations for further work.
- (vi) To speak at Group meetings and outside events as appropriate and reasonable.

### **Membership**

- (i) The Group will have a maximum of eight members. There will be two members from the NICPR Research Team (1 of the co-managers at the Research Fellow) and the remaining places will be filled by people with CP, their families and friends.
- (ii) Membership would normally last for two years however there is no minimum term and there is the opportunity to continue for a third year. After two years of membership, the opportunity to participate would be opened up to new people. Rotation of the membership will be staged to ensure that continuity is maintained.
- (iii) Members of the Group are expected to be interested in PI and CP research.

### **Review**

- (i) The Group will set objectives and review objectives from the previous year every March/April. The Group will evaluate progress each year in October.

## **Meetings**

- (i) Formal meetings will be held twice per year (March/April and October).
- (ii) Meetings will be held at Queen's University Belfast but can be moved as desired by members.
- (iii) Meetings must have a minimum of four members to take place with one of the NICPR co-managers present at each meeting.
- (iv) The NICPR Research Fellow and Administrative Assistant will organise the meetings. The Chair will be rotated amongst the members. Chair Training will be available for those who wish to Chair a Group meeting.
- (v) Topics for the agenda will be generated via the NICPR community mailing list, NICPR PI webpage and members of the PI Group.
- (vi) Papers will be circulated two weeks in advance of the meeting by email.
- (vii) Non-members will be invited to PI Group meetings depending on the expertise required.
- (viii) The NICPR Administrative Assistant will provide secretarial support for the Group. Minutes will be agreed by all members of the Group who attended the meeting.
- (ix) Informal communication to be instigated through email and a web based forum between meetings.
- (x) Group members may be invited to provide specific advice and expertise as required.
- (xi) Sub-groups may be convened to work on specific issues as appropriate.

## **Sharing of information and resources**

- (i) Information will be shared by email but members can request information by post. Confidential information may only be shared at face-to-face meetings.
- (ii) A web-based forum may also be used to facilitate sharing of documents and ideas between Group members.
- (iii) Information about the Group's activities will be shared on the NICPR website as appropriate.