

Alder Hey Clinical Research Facility (CRF)

Parent and Carer Research Forum

Terms of Reference

1 Background

- 1.1 One of the main aims for the Alder Hey Clinical Research Facility (CRF) Parent/Carer Forum is to support the design and delivery of clinical trials involving children and adolescents suffering with chronic and long-term conditions.
- 1.2 Parents and carers will be invited to be part of a forum to support a variety of studies being undertaken within Alder Hey CRF and across UK and Europe. The Forum will work alongside researchers to improve resources and play an integral role in the development of a wide range of paediatric studies.

2 Remit of the Forum

- 2.1 The forum will:
 - Comment on research studies giving comments and advice from a parent/carer perspective
 - Provide input into focus groups when required
 - Design patient information sheets to be used by families
 - Comment on data analysis and assist with the dissemination of the research project findings to relevant stakeholders including parents, young people, and clinicians
 - Members may be asked to attend other meetings as co-applicants with researchers to assist specific studies
 - Members may be asked to attend conferences, workshops and other events to promote the work of the group
 - Members may be involved with social media groups to support and promote the work of the group.
 - Members of the forum will receive relevant training to support them in their role.

3 Membership

3.1 Membership will include:

- Forum facilitator (Sammy Ainsworth)
- 15-20 parents who have a child/young person with long term and chronic health conditions.
- Parents are invited to be involved from both the North West and across the country.

4 Frequency and Format of meetings

- 4.1 The Forum will meet bi-monthly at Alder Hey Children's Hospital, Institute in the Park, Liverpool. Meetings will be held at convenient dates and times of members
- 4.2 The Parents Forum will be chaired by a nominated member.
- 4.3 The group will be attended by some members in person and some members will take part virtually, for example via Facebook, Twitter etc
- 4.4 The Parents Forum will be supported by the Patient Involvement team at Alder Hey CRF

5 Expenses

- 5.1 Members will be offered travel and out of pocket related expenses for attending meetings.
- 5.2 Further information about what can be claimed and how to claim it will be given to each member prior to their membership commencing.

6 Accountability

- 6.1 The Forum will be accountable to the Patient Involvement Lead.

7 Internal Evaluation

- 7.1 After each meeting members will be asked to reflect and consider the process of involvement and progress made with key activities. This information will be collated and fed back to the relevant parties. The Patient Involvement team will be responsible for collating and feeding back findings.

8 Confidentiality

- 8.1 Group members must not communicate any confidential information that they learn as a result of being a member of the Forum.

December 2017

