

Paediatric Heart Disease Patient & Public Involvement Group

This document explains why the Paediatric Heart Disease Patient and Public Involvement (PPI) Group has been established, how it is run, its purpose and the responsibilities of those attending.

Purpose:

What is the role of the group?

The broad purpose of this PPI Group is to actively collaborate with researchers and clinicians in the NHS and its University partners to help deliver high quality research into diagnosing and treating children and young adults with heart disease. The new developments that will be discussed by this group involve (but is not limited to) medical devices and imaging.

When was the group established and by whom?

This group was established in December 2018 by the National Institute of Health Research (NIHR) Cardiovascular MedTech Co-operative at Guy's and St Thomas' NHS Foundation Trust (GSTT), in partnership with Evelina Children's Heart Organisation (ECHO). The MedTech Co-operative sits within the School of Biomedical Engineering and Imaging Sciences (BMEIS) at King's College London (KCL) University and is supported by the Biomedical Research Centre (BRC) at GSTT.

What are the aims and responsibilities of the group?

The key objective of the group is to help guide medical research, making it more effective, efficient and patient focussed. The majority of content presented to this group comprises of early stage medical research, where presenters are preparing for grant applications. In this case and for all other presentations received by the group at meetings, an opportunity for discussion is provided. Your suggestions focussed on improving patient experience and the patient pathway can improve the planning and design of research projects and how these are carried out. It may be possible for members (individuals or whole group) to be more involved in research projects in an advisory role if requested and feasible, should you be interested and have the capacity. A key responsibility for the group is to review material used for patient recruitment to studies e.g. 'patient information sheets' and 'lay summary' documents that will be given to prospective patients and their relatives, and to provide feedback on new procedures and/or how medical technologies are used. This will improve how medical research is presented to participants and improve the patient experience. Feedback provided by group members to presenters is used at the discretion of the presenters. However, there is an expectation that presenters will feed back how suggestions were used back to the members.

Terms of reference

Membership - who is membership of the group open to?

Membership is open to patients and the general public (aged 16 and above) receiving treatment or investigation for heart conditions present from birth, or have in the past. Membership extends to carers / family members of those mentioned above. Experience of attending PPI groups in the past is not a requirement. The main requirement is that you are enthusiastic about helping research into heart disease and improving children's health. Each meeting is restricted to ten (10) people for the "group", which does not include facilitators. A minimum of two members are required to be present at meetings. Confirmation of your attendance should be provided at least one week in advance of scheduled meetings, if possible. We also welcome your contributions by phone, email, and video connection, where possible.

No defined period of membership exists but members are offered the opportunity to review their membership annually. Feedback provided by members should be given in a constructive, kind and concise manner. Meetings are led by the chair, or the vice chair (should the chair be unavailable) within the group. Chair and vice chair are elected by majority vote by group members for a duration of one year and may serve a maximum of two consecutive terms (two years) in the same role. A compulsory resting period of one year is required before being eligible for re-election of the same role. If equal number of votes are cast for a given role, a joint role will be considered.

Practical terms of the group's way of working

Frequency

Face-to-face meetings as well as audio-video participation of the core group (up to ten members) is approximately every three months, depending on the number of expression of interest forms received and the range of involvement activities undertaken. Meetings are held at the ECHO Office or St Thomas' Hospital. Meetings are organised by a named facilitator who communicates with all group members.

During busy periods e.g. near major research grant application deadlines, there is often an increase in requests for PPI. As a result, ad hoc meetings may be arranged, with a minimum of one week notice provided. In addition, you may be asked to review documents circulated between meetings, providing feedback in a way that is best for you.

Topic of discussion

The research discussed by this PPI group concerns children's health and heart disease. Investigations under discussion typically involve medical devices and imaging. There is scope to extend this to cover other treatments / studies, depending on the needs of the researchers. The agenda is led by new research studies created within GSTT / KCL, mid-term

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discussions for on-going studies, end of project discussions - including dissemination of results for lay people / research participants.

Information dissemination and discussion

An agenda with information about the projects along with relevant documents are emailed to members at least one week in advance to allow time for review. During the meeting, researchers and clinicians are given at least 10-15 minutes to present their studies. After each presentation, PPI members are invited to feedback in a constructive and concise way.

Minutes of each meeting are circulated to the group. Any amendments to minutes are discussed at the following meeting and agreed. Minutes are edited for relevance and circulated to the participating researchers. Meetings are advertised in advance to the School of BMEIS, the BRC at Guy's and St Thomas' Hospital, ECHO, Evelina Children's Hospital, and wider King's Health Partners.

Confidentiality

Material provided to and discussed by the group must remain confidential and should not be discussed with anybody outside of the group. This is because there may be intellectual property involved: commercially sensitive information and copyright issues. We request that members agree to keep these matters confidential.

Observers

Observers are permitted to join PPI group meetings for the purpose of PPI recruitment or to generally learn about PPI. A maximum of two observers per meeting is permitted and all observers are required to maintain the same level of confidentiality as members. Observers are asked not to participate in discussions related to research under review by members but are welcome to ask questions for personal clarification.

Recruitment of new members

Recruitment of new PPI group members will be managed by MedTech Co-operative staff with the support of ECHO and the BRC. PPI group members are encouraged to direct potential members to staff for further information and to arrange lay member training, if required.

Organisation

The MedTech Co-operative is responsible for managing the group. This includes organising meetings, meeting content and minute taking. When necessary, MedTech Co-operative staff will communicate follow-up items with all members to ascertain required feedback.

Responsibilities of elected chair(s):

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- Chair meetings, enabling adequate discussion by good time keeping
- Ensure all feedback is delivered in a constructive and concise way
- Review meeting minutes in consultation with MedTech Co-operative staff prior to dissemination

Expenses

Cold refreshments (sandwiches, fruit, crisps, water) is provided during meetings. Travel expenses up to the value of a London Zone 1-6 travel card are reimbursed.

Data privacy

In becoming a member of this group we may have / will obtain personal information from you, or otherwise provided to us e.g. for expense reimbursements. The types of information collected might include names, e-mail address, postal address, telephone number and credit/debit card details. We will use your personal information for internal administration purposes directly related to the group and will not share it without your written consent. We also take appropriate measures to ensure that your information is kept secure and up to date and kept for so long as is necessary for the purpose for which it is used.

By joining this group and providing this information you consent to the collection and use of any information you provide in accordance with the privacy statement above.

Review

MedTech Co-operative Managers review the relevance and value of the group's work and review these terms of reference annually. This is necessary to maintain and improve the group's effectiveness to help develop research and keep the group at the forefront of this process. MedTech Co-operative Managers are happy to receive suggestions from group members for consideration in this process where appropriate.

Signed:

Name: _____

Date: _____

Signature: _____