



Role Description

Position: Patient and Public Voice Representative, Lifelong CHD Network

Staff Contacts: Joe Eurell, Network Manager
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1. About the Lifelong Congenital Heart Disease Network

The Lifelong Congenital Heart Disease (CHD) Network brings together NHS professionals working across London, Bedfordshire, Hertfordshire, Kent, Essex, Suffolk, Surrey, Sussex and further afield to ensure that CHD patients, families and carers receive equal access to specialist support across a lifetime of care. The network's values are at the heart of everything we do.

- High quality and responsive care
- Engaging with patients and network partners
- Education, research and innovation
- Supporting patients and families through their lifetime
- Patient education and empowerment

2. Patient and Public Voice (PPV) Representatives

PPV representatives are people who are willing to share their perspective and experience of the NHS to inform health services in a range of different ways. PPV representatives include patients, service users, carers, families and other members of the public.

3. Purpose of the Role

The Lifelong CHD Network is committed to ensuring that the views of patients, family members and carers are included in the decision making process. The input of PPV representatives allows the network to make fully informed, patient focussed decisions that affect patients with CHD and influence the long-term strategy of its network of hospitals.

4. Benefits of the Role

- Supports the network and the wider CHD community
- Pass on experiences that could provide learning opportunities or service improvements
- Gain exposure to senior NHS stakeholders and knowledge of the healthcare system
- Peer support from fellow PPV representatives
- The flexibility to commit as much or as little time as a person can give
- Reimbursement of expenses so that representatives are not left out of pocket



5. Main Duties and Responsibilities of the Role

- To actively contribute to discussions that help provide high-quality care
- To attend meetings or events and allocate sufficient time to prepare
- To contribute to the development and review of guidance and information materials
- To promote the network and the role of PPV representative by engaging with the local community, capturing the views and concerns of local people about health and wellbeing.
- To represent the views of a diverse network of CHD patients, families and carers and not just those held personally.
- To conduct oneself in line with the values of the Lifelong CHD Network and not damage its image, reputation or credibility.
- To complete training as required to undertake the role effectively
- To maintain confidentiality by following the confidentiality agreement (Appendix I)

6. Types of PPV Representative

We recognise that PPV representatives will have different skills, interests and time that they can give, so we have created several roles to best suit the individual around family, work and other commitments.

PPV Type	Description	Meetings Attended	Benefits
PPV Network Board Representative	<p>The CHD Network Board is formed of clinical and non-clinical NHS professionals, including medical, nursing and managerial staff. The group discuss network business and provides guidance and decision making on issues or concerns that have escalated to them. Each meeting begins with a Patient Story and PPV has a recurring slot on the agenda.</p> <p>A PPV Network Board Representative has a seat on the Board and must have the confidence to actively contribute patient feedback in response to agenda items and present PPV Working Group progress reports.</p>	<p>CHD Network Board Quarterly 2 hours per meeting 30 minutes to 1 hour preparation</p> <p>Must attend a minimum of 3 out of 4 meetings per year.</p>	<ul style="list-style-type: none"> ✓ Exposure to senior NHS stakeholders ✓ Experience for your CV ✓ Share your experiences ✓ Influence decision making ✓ Peer support ✓ Reimbursement of expenses



	This representative can also attend all other PPV meetings, including PPV Working Group meetings.		
PPV Working Group Representative	<p>The PPV Working Group is a smaller, more informal group, including NHS professionals, charity staff and other PPV representatives who collaborate to achieve a specific goal. Issues addressed should be representative of the network's population as a whole. The Working Group provides a progress report to each Network Board meeting.</p> <p>A PPV Working Group member should be able to drive meetings, table agenda items and share their own experiences, along with members of the CHD community that they have engaged with in their role.</p>	<p>Working Group Meetings Bi-monthly 45 minutes per meeting 15 to 30 minutes preparation</p>	<ul style="list-style-type: none"> ✓ Experience for your CV ✓ Share your experiences ✓ Influence decision making ✓ Peer support ✓ Reimbursement of expenses
PPV Flexi Representative	This PPV member does not have a fixed commitment or attend any core meetings. Instead, they contribute on an ad-hoc basis, for example, reviewing network documentation, taking part in online forums or attending stand-alone network meetings and events as desired.	Ad-hoc attendance of meetings and events with no fixed commitment	<ul style="list-style-type: none"> ✓ Share your experiences ✓ Influence decision making ✓ Peer support ✓ Reimbursement of expenses ✓ Flexible time commitment



7. How you will be Supported in this Role

We are committed to supporting PPV representatives and removing any barriers that may prevent them from contributing to the network. We also wish to ensure that representatives reflect the diversity of our patient population and that we hear a range of voices and opinions. Therefore the Network Management Team shall:

- Reimburse reasonable expenses for each meeting upon production of receipts¹.
- Arrange an introductory meeting with key member(s) of the network leadership team before your first board meeting.
- Provide formal training to help you undertake your PPV representative role to the best of your abilities.
- Identify opportunities for further training and support that may help you better fulfil the role.
- Provide named contacts that you can get in touch with in the event of ad-hoc queries about your role or the Lifelong CHD Network as a whole.
- Send copies of meeting papers ahead of time so that you have enough time to prepare (papers are usually sent 2 weeks before a Board or Working Group meeting).
- Allow you to ask questions or discuss queries before or after meetings.
- Support a flexible time commitment outside of core network meetings.

¹ To be agreed in advance with a Lifelong CHD Network or Guy's and St. Thomas' staff contact



Appendix I

Confidentiality Clause CONFIDENTIALITY

**(THIS INFORMATION SHOULD BE KEPT
IN A SAFE PLACE FOR FUTURE REFERENCE)**

During the course of your volunteering activity, you may have access to see or hear information of a confidential nature. You are expected to use your discretion and maintain confidentiality about information relating to all aspects of your volunteering activity.

Disclosures of information relating to medicines safety including incidents or errors, audit data, patients, members of staff or that which you acquire during the course of your volunteering activity may only be disclosed with the agreement of your Supporter. The Data Protection Act 1998 renders an individual liable for prosecution in the event of unauthorised disclosure of information, or action for civil damages under the same Act.

Should you have any cause for concern about confidentiality you should discuss this with your nominated supporter within the organisation: Name: Dr David Wood, Consultant Physician.

Contact via Annette Fogarty, Senior Patient Safety Manager on 0207 188 3512 or email annette.fogarty@gstt.nhs.uk



CONFIDENTIALITY

I have received, read and understood the Guy's and St Thomas' NHS Foundation Trust Confidentiality Clause.

Name
(Please print)

Signature

Date

PLEASE RETURN TO:

CHDnetwork@gstt.nhs.uk