



East Midlands
Congenital Heart Network

Patient and Public Voice Volunteers

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East Midlands Congenital Heart Network

Role of the Patient and Public Voice Volunteer (PPVV)

May 2023

Document Control and Governance

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The main purpose of the role

The role of the PPV representative is to represent the views and experiences of patients & parents. The patient and public voice is vital in helping to improve the care that is provided across the East Midlands Congenital Heart Disease Network (EMCHN).

We welcome people from a diverse background to help the Network reach all members of our community with information about congenital heart disease.

The role of the PPV Volunteer

- Ensure that the patient/parents voice is heard and listened to.
- To help to drive transformation of CHD services.
- To represent the views and experiences of patients and parents to help influence change. Your own lived experience is important, but it is also important to represent everyone's views.

Time commitment required

- Attend and contribute to PPV Group meetings in person or via teleconference by Microsoft teams. Meetings will be approximately 4 times a year.
- We may ask you to review patient information leaflets, documents about services including information to be published on our website.
- PPV's will have the opportunity to attend the CHD Board Meetings to represent the patient and public voice views and opinions. Board is held 4 times a year either virtually or as a face to face meeting.
- To review feedback given by patients, their families and service users as to how services across the EMCHN are working.

Skills and experiences

Whilst the skills and experiences listed below are helpful, they are not essential; We want everyone to feel welcome. Living with congenital heart disease, or caring for someone with congenital heart disease makes you an expert in this subject. Training and support can be provided for people if required.

- Personal experience of a CHD journey; You may be a past user of NHS services related to congenital heart disease (this could be as a patient, parent or carer) or as a representative of a patient support group (national or regional).
- Experience of speaking in large groups.
- Ability to understand and evaluate a range of information
- Experience of working in partnership with healthcare organisations or programmes.
- Ability to display sound judgement and objectivity.
- Have an awareness of, and commitment to, equality and diversity.
- Understand the need for confidentiality. You will be required to maintain confidentiality and ensure information is only shared outside of the EMCHN on the agreement of the EMCH Network Board.
- Be able to commit to the 'seven principles of public life' known as the 'Nolan Principles' selflessness, integrity, objectivity, accountability, openness, honesty, leadership.
- To be able to represent the views of other patients and parents who have had a CHD journey.
- Be able to communicate your thoughts and ideas.
- Have an interest in helping to improve the quality of care that is provided.
- Be able to reflect and seek support and advice whenever you feel it is needed.
- Be able to put aside previous personal and organisational relationships, and not lobby or advocate for a particular interest or group including yourself.

We recommend deferring involvement for a period of 12 months from a significant event such as bereavement. Previous experience of working in a PPV role is helpful but is not necessary as training and support will be given. We welcome people who use other forms of communication such as sign language, Makaton or braille etc.

Application process

- Application forms can be found on the East Midlands Congenital Heart Network website (www.emchnetwork.nhs.uk) or via the QR code on our poster.
- We will acknowledge receipt of your application form by email.
- Applications will be shortlisted by the EMCHN Network Manager, Clinical Director and Lead Nurse.
- Applications will be assessed against the skills and experience required, outlined in this application pack. Selection will be made on the basis of the content of the application form.
- Interviews will take place via video conference.
- Following a successful interview, Disclosure and Barring Service (DBS) clearance (formerly known as a 'Criminal Records Bureau' (CRB) check') – basic check will be performed by University Hospitals of Leicester Human Resources Department.
- All applications will receive a successful or unsuccessful notification. The successful notifications will include information about next steps.

Diversity and equality of opportunity

EMCHN values and promotes diversity and is committed to the equality of opportunity for all. To help us understand if we are achieving this, we ask you to fill out an **Equal Opportunity Monitoring Form** as part of the application process.

Please let us know if you have support needs so that we can understand how we can support you to participate fully.



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PPV Volunteer Overview

The role of the PPV representative is to represent the views and experiences of patients & parents. The patient and public voice is vital in helping to improve the care that is provided across the East Midlands Congenital Heart Disease Network (EMCHN).

We welcome people from a diverse background to help the Network reach all members of our community with information about congenital heart disease. We are committed to providing a rewarding and productive patient and public voice volunteer experience.

The purpose of this agreement is to outline the commitments from the EMCHN in supporting PPV Volunteers and expectations of the EMCHN in respect to individuals who wish to become PPVV.

This agreement is not intended to be legally binding and does not involve having a contract with either University Hospitals of Leicester as the host or with the East Midlands Congenital Heart Network.

This Agreement means that you can access University Hospitals of Leicester NHS Trust (the organisation that hosts the East Midlands Congenital Heart Network) solely for the purposes of patient and public voice work on the terms set out below.

This agreement does not give rise to an employment relationship between you and the Network. This means that you will not get paid for any volunteering work that you undertake other than reimbursement of travel expenses and payment of volunteer attendance fee.

What we will provide

- Sufficient notice of scheduled meetings
- Opportunity for training to support the PPVV role
- Timely reimbursement of expenses related to PPV work, in accordance with PPV Expenses and Payments Standard Operating Procedure
- An environment that supports co-production

The Patient and Public Voice (PPV) Volunteer Agreement

Following a successful application process, you will be provided with a Welcome Pack. This will give you information about the Network, how to claim expenses.

You will be supported by the Lead Nurse and Network Manager for the East Midlands Congenital Heart Network who will also provide any help, training and additional information as required.

As a PPV Volunteer for the EMCH Network you would be expected to adhere to any relevant policies and procedures within University Hospitals of Leicester NHS Trust. If you wish to view any of these documents, please ask the Lead Nurse for the Network who will be happy to share these with you.

Commitments

As a PPV Volunteer, I agree to the following aspects of the role:

- Attend and contribute to PPV Group meetings in person or via teleconference by Microsoft teams. Meetings will be approximately 4 times a year.
- Contribute to reviewing patient information leaflets, documents about services including information to be published on our website.
- Attend the CHD Board Meetings to represent the patient and public voice views and opinions when requested to do so.
- Provide feedback given by patients, their families and service users as to how services across the EMCHN are working.

Agreements

As a PPV Volunteer, I agree to:

- Advocate the views of the service users
- Support service development with a range of views and opinions
- Always act in a calm and professional manner.
- Always be respectful of everyone else's views and ideas.
- Treat everyone with respect and without discrimination
- Escalate concerns to the Network Team

- Inform the EMCH Network Lead Nurse in writing if I wish to leave.
- Always act in accordance with the values of University Hospitals of Leicester NHS Trust who host the EMCH Network.

They are:

<p>We treat people how we would like to be treated</p> 	<ul style="list-style-type: none"> • We listen to our patients and to our colleagues, we always treat them with dignity and we respect their views and opinions • We are always polite, honest and friendly • We are here to help and we make sure that our patients and colleagues feel valued
<p>We do what we say we are going to do</p> 	<ul style="list-style-type: none"> • When we talk to patients and their relatives we are clear about what is happening • When we talk to colleagues we are clear about what is expected. • We make the time to care • If we cannot do something, we will explain why
<p>We focus on what matters most</p> 	<ul style="list-style-type: none"> • We talk to patients, the public and colleagues about what matters most to them and we do not assume that we know best. • We do not put off making difficult decisions if they are the right decisions • We use money and resources responsibly
<p>We are one team and we are best when we work together</p> 	<ul style="list-style-type: none"> • We are professional at all times • We set common goals and we take responsibility for our part in achieving them • We give clear feedback and make sure that we communicate with one another effectively
<p>We are passionate and creative in our work</p> 	<ul style="list-style-type: none"> • We encourage and value other people's ideas • We seek inventive solutions to problems • We recognise people's achievements and celebrate success

Health and Safety

I will comply with policies and procedures related to Health and Safety (whether statutory or Trust). As a PPV Volunteer, I will always act in a responsible manner, working within the Health and Safety Guidelines. I will take reasonable care for the health and safety of myself and others who may be affected by my acts, or failures to act.

Confidentiality

I understand that in my role as a PPV Volunteer, I may be privileged to sensitive and confidential information. If I use or disclose confidential information, it will be regarded as a serious disciplinary matter, and I may be personally liable under provisions of the Data Protection Act.

Child Protection

I agree to carry out my role as a PPV Volunteer in accordance with the Trust's Safeguarding Policy. Copies of this policy are available from the EMCH Network Lead Nurse. Volunteer are asked to escalate any areas of concern to the Network team.

Disagreements between group members

In the rare event of a disagreement between individual members of the PPV Group, the Chair and Vice Chair of the group will try to resolve the issue within the group meetings in the first instance. If the situation continues and is not resolved, then a facilitated meeting between the people affected will be arranged. The Lead Nurse for the Network and Clinical Psychologist (co-facilitator) will support everyone involved to try to find resolution.

Communications and Social Media

The EMCHN uses Twitter to promote PPVG activity. Members would need to consent to sharing photographs and activity of the PPVG via Twitter platforms. The Network does not use Facebook or Instagram social media platforms.

I agree to only use social media to promote and advertise the work of the EMCHN. I will not use social media in any of its forms to publicly criticise or make negative comments about any staff or other members of the PPV Group. Failure to comply with this may result in being asked to step down as a PPV Volunteer.

Equal opportunities

I agree to carry out my role as a PPV Volunteer in accordance with the Trust's Equal Opportunities Policy. Copies are available from the EMCH Network Lead Nurse.

PPV Work copyright and other intellectual property rights

I confirm that I understand that any work I produce in my role as a PPV Volunteer for EMCH Network is copyrighted to the Network and not to me. I am aware that I can have copies of the work that I produce to keep for my own purposes, but I accept that the work itself belongs to the Network.

I have read and understand this agreement and agree to abide by University Hospitals of Leicester NHS Trust policies and procedures, including Child Protection, Business Conduct, Equal Opportunities, Health and Safety, Confidentiality and Infection Control. I understand that if I wish to view these documents that I can ask the EMCH Network Lead Nurse for copies.

I understand that the Rehabilitation of Offenders Act 1974 (Exceptions) Order requires me to declare any criminal convictions whether spent or unspent before I can work with vulnerable groups in a voluntary service capacity and that any such offences must be declared as part of an Enhanced Disclosure Barring Service check. This means that if I have ever been cautioned or convicted of any offence within my lifetime, I will have to declare it.

I understand that during my voluntary activity for the Network, I may have access to information designated to be of a confidential nature. I must not divulge, publish or disclose such information without prior written consent from the University Hospitals of Leicester NHS Trust and The EMCH Network.

Declaration of interests and ensuring public confidence

If you have any business or personal interests that might be relevant to the work of the group, and which could lead to a real or perceived conflict of interest, you must declare them verbally at the start of any relevant meetings. If there is anything in your professional history that, if brought into the public domain, may cause embarrassment of disrepute to the organisation, please provide further details to the Lead Nurse for the Network.

How will EMCHN take care of my personal information?

Personal data:

- Personal information supplied on your application to become a PPV Volunteer for the Network will be stored securely. It will only be used for the purposes of PPV engagement work and will not be shared outside of this agreement.
- If you choose to complete the diversity monitoring form, the information will be stored securely and anonymously and will never be linked to your personal data. This data will be kept after you have completed your tenure as PPV Volunteer.
- All data will be stored on a secure drive within the IT system at University Hospitals of Leicester and will only be accessed by the Network team comprising of Network Managers, Admin Support and Lead Nurse.
- The EMCH Network will not transfer your data to any third parties.
- The EMCH Network will retain your data for the full 4 years of your tenure as a PPV Volunteer or sooner if you wish to leave the role before this time. After this time your data will be removed securely.
- All emails sent will use the 'Bcc' option to ensure emails are kept secure and hidden.

PPV Meetings:

- Meetings will be held remotely via Microsoft (MS) Teams or face to face (venues to be arranged).
- You will receive an invite to meetings via Network email using Bcc to ensure emails remain hidden.
- You will need to download the MS Teams App on your device/PC.
- We request that meetings are recorded via MS Teams to assist with note taking. Permission will be requested at the start of each meeting.
- The video will remain within the MS Team Meeting where it occurred and will not be downloaded for any other use without your express consent. Once the notes have been written up the recording will be deleted.
- The video can be accessed by the facilitators of the meeting and the admin support only. No other members of the PPV Group will be able to access the recording.

Declaration

I agree to conduct myself in a responsible manner whilst undertaking the role of Patient & Public Voice Volunteer for the EMCH Network, to always follow Trust values and to endeavour to serve patients and families and to foster good patient representative / staff relationships.

Please sign below to certify that you understand and agree with the above:

Signed: -

Print Full Name: -

Date: -