The Role of the Patient & Public Voice (PPV) Partner for the North West, North Wales and Isle of Man Congenital Heart Disease Network (NW CHD Network)

Main purpose of the role

The role of the PPV representative is to represent the views and experiences of people affected by paediatric cardiac conditions and adult congenital heart disease. The patient and public voice is vital in helping to improve the care that is provided across the NW CHD Network. We welcome people from a diverse background to help reach all members of our community with information about congenital heart disease.

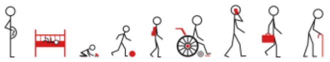
The Role of the PPV Representative

- Ensure that anyone who is affected has a voice and is heard and listened to
- Be a 'critical friend' to challenge services that need to improve
- Represent the views and experiences of patients and parents
- Attend and contribute to PPV meetings in person, or via teleconference
- You will have the opportunity to attend the CHD Board Meetings
- You may be asked to set aside time for reading so that you know what to expect of the meeting/group you are involved with
- Provide feedback as to how services across the NW CHD Network are working
- If you are an active member of a charity or support group, we may ask you to see what their membership's opinion is on a particular subject. This may help to get a wider view of patients' and parents' views.
- You will be required to maintain confidentiality and ensure information is only shared outside organisations with the agreement of the NWCHD Network Board.
- We may ask you to review patient information leaflets, documents about services including information to be published on our website.

Skills and abilities (essential)

We want everyone to feel welcome. Living with or being a family member of someone living with congenital heart disease makes you an expert in this subject. In addition, you must:

- Be committed to equality and diversity
- Understand the need for confidentiality
- Be able to display sound judgement and objectivity
- Be able to communicate your thoughts and ideas
- Be willing to seek support and advice for yourself whenever you feel it is needed
- Put aside previous personal and organisational relationships, and not to lobby or advocate for a particular interest or group including yourself



- Act in a respectful way and treat everyone you come into contact with equally and without discrimination.
- Be respectful of everyone else's views and ideas at all times
- You will act in all times in accordance with the values of Alder Hey Children's Hospital, who host the NW CHD Network. They are:

excellence	We pride ourselves on the quality of our care, going the extra mile to make Alder Hey a safe and special place for children and their families.
innovation	We are committed to continually improving for the benefit of our patients.
openness	We are open and honest and engage everyone we meet with a smile.
respect	We show that we value every individual for who they are and their contribution.
together	We work across the Alder Hey community in teams that are built on friendship, dedication, care and reassurance.

Other skills that may be helpful – but not necessary

- Experience of speaking in large groups
- Ability to understand and evaluate a range of information
- Previous experience of representing patients in healthcare forums
- Experience of working in partnership with healthcare organisations or programmes
- Ability to represent the views of other patients and parents who have had a CHD journey.
- We welcome people who use other forms of communication. Please discuss your needs with us and we will do our best to accommodate.

Experience

- Personal experience of a paediatric heart problem and/or adult congenital heart disease
- You may be a current user of the service (we recommend not getting involved within 12 months of a significant event such as bereavement)
- You may be a past user of NHS services (this could be as a patient, parent or carer) or as a representative of a patient support group (national or regional)

- Previous experience of working in a PPV role is helpful but is not necessary as training and support will be given

Time commitment

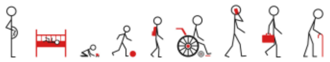
We recognise that not everyone will be able to commit to everything. Whatever time you can commit to will be valued and will be helpful:

- The PPV meetings are held monthly, and they last for two hours.
- The meetings are recorded so that accurate meeting notes can be taken. No-one else has access to these recordings.
- The NW CHD Board meets every 3 months. You will have an opportunity to attend this meeting alongside the chair of PPV Group. This will be done in rotation to ensure everyone has a chance to attend. The Board meetings last for 2 hours.
- If you wish to get involved in smaller groups looking at a specific area this may mean attending meetings in addition to the above, which will vary in time and how regularly they meet.
- We encourage members to commit to one year as a minimum term, up to a maximum of four years.
- We may also ask for your input via email or post.
- Most meetings will be held virtually via Microsoft (MS) Teams. The PPV Group aim to meet face-to-face at least once a year.
- You can refuse to do anything that you feel uncomfortable with or find too stressful.
- We expect members to try and attend regularly although recognise that not everyone can make every meeting. If no engagement for a period of 6 months, then the chair of the PPV group will contact you to ask if you wish to continue in the role. If no further engagement for another 3 months, then a decision will be made to remove you from the PPV group. You will be notified of this decision by email.
- You have the right to step down at any time, knowing that it will not affect any future care or treatment

Next steps

If you are interested in this role contact Linda Griffiths (Lead Nurse for The NW CHD Network) email: linda.griffiths@alderhey.nhs.uk

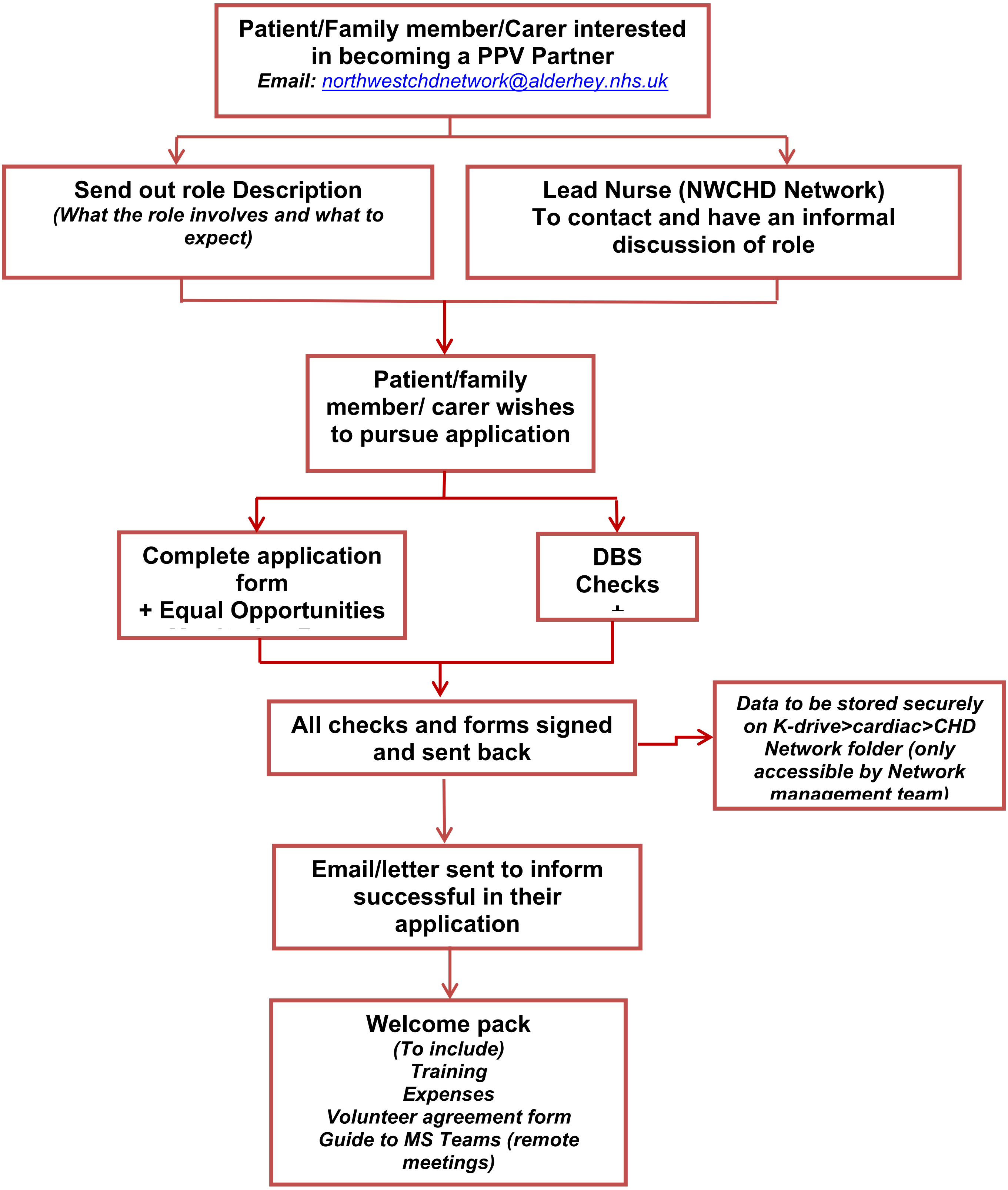
Thank you for considering this important role and making sure that the patient and parent remains at the heart of our services



Patient & Public Voice (PPV Partner)

North West, North Wales and the Isle of Man CHD Network

Pathway



Patient/Family member/Carer interested in becoming a PPV Partner
Email: *northwestchdnetwork@alderhey.nhs.uk*

Send out role Description
(What the role involves and what to expect)

Lead Nurse (NWCHD Network)
To contact and have an informal discussion of role

Patient/family member/ carer wishes to pursue application

Complete application form
+ Equal Opportunities

DBS Checks

All checks and forms signed and sent back

Data to be stored securely on K-drive>cardiac>CHD Network folder (only accessible by Network management team)

Email/letter sent to inform successful in their application

Welcome pack
(To include)
Training
Expenses
Volunteer agreement form
Guide to MS Teams (remote meetings)