South Wales and South West Congenital Heart Disease (CHD) Network

Volunteer Role Description: Patient and Public Voice Representative

Role title	Patient and Public Voice (PPV) Representative
Named volunteer lead	CHD Network Lead Nurse
Location	South Wales and South West of England (SWSW)
Our vision	The CHD Network is keen to have the patient and public voice at the heart of all that we do, and to build a strong and supportive relationship with our volunteer partners. We believe that it is vital that our patients/families views are heard and help to shape and improve services across the Network. To ensure PPV representation is as effective as possible, the CHD Network would like to involve a variety of patient representatives.
Role purpose	The CHD Network values the important role that PPV representatives play in bringing their perspectives to improve patient and family experiences of congenital heart disease (CHD) care across the region. People with lived experience are experts by experience. These insights, both positive and negative, are essential in supporting meaningful engagement in discussions around quality, service improvement, and service design.
Role suitability	Key skills and experience: - Lived experience of NHS services relating to congenital heart disease, as a patient, parent, or carer, providing valuable insight into care pathways and patient needs. - A strong interest in contributing to the improvement of care quality across the Network. - Ability to approach discussions objectively, offering balanced and constructive input in a multi-professional environment. - Commitment to collaborative working, engaging respectfully with other PPV representatives, patients, families and healthcare professionals.

	- Effective communication skills, with confidence to express views and contribute meaningfully to discussions. - Experience or ability to review patient-facing materials (e.g. information leaflets, service documents, newsletters) and provide constructive feedback. - Willingness to seek guidance and support when needed. - Strong interpersonal skills, including confidentiality, active listening, empathy, and a collaborative approach.
Terms and conditions	Membership is voluntary and is normally for a period of 3 years. There is no obligation to remain part of the group; however, written notice is requested if you choose to leave so your details can be removed in line with data protection requirements After a 3-year period, membership may be reviewed and extended for a further 3 years by mutual agreement. We encourage representatives to be involved at a level that suits their capacity, recognising that availability may change due to work or family commitments. Membership can also be paused and resumed, for example during periods of illness. Due to the potentially emotional nature of this role, it is recommended that patients wait at least 12 months post-discharge before becoming involved. Members are expected to: - Maintain confidentiality and be mindful of the sensitive nature of discussions. - Share information externally only with agreement from the SWSW CHD Network Board. - Act in accordance with NHS England / NHS Wales Joint Commissioning Committee (JCC) policies, and uphold equality, diversity, and inclusion principles. - Treat all individuals with respect and without discrimination. Members may step down at any time, and doing so will not affect any current or future care or treatment.

Getting involved	There are a range of opportunities to contribute, depending on capacity and interest. These may include: - Providing feedback and insights to inform Network decisions, ensuring contributions are balanced, objective, and in the public interest. - Reviewing and advising on patient-facing materials to ensure accessibility and relevance. - Sharing lived experience to support service design, decision-making, and continuous improvement. - Contributing to projects aimed at improving patient experience and quality of care. - Identifying opportunities for service improvement based on experience. - Collaborating with healthcare professionals to co-design services and resources. - Suggesting innovative ideas to improve care for people with CHD. - Supporting the gathering of feedback from patients and families where appropriate. - Participating in meetings and engagement events, representing patient and family perspectives. - Attending Network Board meetings (typically held online quarterly), including preparation through reviewing agendas and papers. - Participating in relevant training to support the role.
Network Board involvement	- PPV representatives are valued members of the Network Board and have the full support of the Chair. - Pre-Board meetings are offered to support preparation, along with post-meeting debriefs if needed. - Representatives from the PPV group provide updates on engagement and activity at Board meetings.
Support and training	- The Network Lead Nurse will provide an induction and offer guidance and ongoing support as needed. - The Network will provide, or signpost to, relevant training opportunities where appropriate.

	- Representatives will receive information and support to enable meaningful participation in meetings. - If concerns cannot be raised during meetings, representatives are encouraged to contact the Network Lead Nurse outside of the meeting.
What's in it for the volunteer?	PPV representatives will: - Be valued and listened to as an equal in all discussions. - Have opportunities to provide informed and constructive challenge. - Receive an induction to the Network and understand the purpose of the Board. - Have opportunities to discuss and reflect on their role with the Network Lead Nurse. - Contribute to projects that directly influence service improvement. - Know that your contribution is helping to improve care for patients with congenital heart conditions across South Wales and the South West. - Connect with other representatives and benefit from peer support. - Have access to Network staff for guidance and support. - Be supported with accessibility needs for face-to-face meetings, with reasonable adjustments made where required. - Be reimbursed for reasonable out-of-pocket expenses, such as travel.
Suggested reading	To find out more about the Network it may be useful to look on the Congenital Heart Disease Network website www.swswchd.co.uk. For further information The Standards and Specifications for Congenital heart Disease (2016) https://www.england.nhs.uk/wp-content/uploads/2018/08/Congenital-heart-disease-standards-and-specifications.pdf There is also useful information to be found in the NHS England Patient and Public Voice Partners Policy (2017) – see appendix 1. patient-and-public-voice-partners-policy-july-2017.pdf (england.nhs.uk)

For further information and support	The lead contact for the patient/parent representatives is the Network Lead Nurse who can be contacted by email: Becky Lambert Becky.Lambert@uhbw.nhs.uk Any concerns should be directed via her.

South Wales and South West CHD Network – Useful Information

Background	The South Wales and Southwest Congenital Heart Disease Network (SWSWCHD Network) was formed in 2016 in response to the NHS England *"Congenital Heart Disease Standards and Specifications".* Congenital-heart-disease-standards-and-specifications.pdf (england.nhs.uk) This report sets out adult and paediatric standards and service specifications for congenital heart disease services in England agreed by the NHS England Board in July 2015 and became effective from 1 April 2016. The standards cover adult and paediatric care in the Level 1 specialist surgical centre (Bristol), the Level 2 specialist cardiology centre (Cardiff) and the Level 3 (peripheral clinics across the South Wales and South West of England Network) local cardiology centres.
Network Vision	Our vision is to be a Network where: - High quality standardised care is delivered in all centres, led by the latest clinical developments, including seamless care between paediatric and adult services. - There is equity of access to services and equitable outcomes, regardless of geography. - There is a strong and sustainable CHD workforce across the Network. - There is a strong patient and public voice partnership with representation from a variety of socio-economic and ethnic groups. - There is a strong and collective voice for Network Stakeholders. - A culture exists of fostering research, innovation, and digital integration.

APPENDIX 1

NHS England Patient and Public Voice Partners Policy

TABLE 1: Summary of PPV partner role descriptions

Role requirements	Role 1	Role 2	Role 3	Role 4
Nature of activity	People choose to attend, respond or comment on **open access engagement** opportunities e.g. responding to online surveys, attending NHS England's Annual General Meeting	PPV partner is invited to attend workshops/events/ focus groups **on a one off basis**	PPV partner is a member of **regular working group meetings** (policy and service design, commissioning reviews, task and finish programmes, etc)	PPV partners are in committees /roles that demonstrate **strategic and accountable leadership and decision making activity or members of groups that make recommendations to committees that have delegated authority of the NHS England Board.**
Level of input	Informs NHS England's work	Informs NHS England's work	Input to NHS England's committees and working groups	Input and shared decision making in NHS England's committees and priority programmes, or involved in making recommendations to committees that have delegated authority from the board
Expenses category (refer to PPV expenses policy)	A (no financial contribution from NHS England)	B (reasonable out of pocket expenses covered)	B (reasonable out of pocket expenses covered)	C ('Expert PPV adviser role', includes involvement payment)