

Congenital Heart Disease Network South Wales and South West Stakeholder Day 2018

Date: Tuesday 10th March 2018

Venue: BAWA, 589 Southmead Road, Filton, Bristol, BS34 7RG

Comments and actions from interactive discussion sessions

Item	Topic, with comments and actions:
1.	<ul style="list-style-type: none"> • What does the network mean to me? • How has the network impacted on me? • What is my role within the network? • What can I do to improve the function of the network?
	<ul style="list-style-type: none"> • Means of information cascade • Gives confidence to patients/families – there is oversight of the pathways/service • Website is source of information for patients/families who may feel ‘lost’ e.g. on centres, pathways • Link across hub and spoke centres – smoothing the pathways • Opportunity for patients to become representatives – cathartic • Patient reps can help address issues through the network • Vital means of communication • Aiming for gold standard care for all points in journey • Opportunity for dialogue and new ways of doing things... what if? • How do we measure the success of the network, particularly amongst patients? Action: Network team to raise with national PREMs¹ team as to whether a question(s) could be included on this
2.	Open discussion at end of network team presentation
	<ul style="list-style-type: none"> • Could we have more focus on midwives (information and increased understanding, a resource pack?) Could this align with our planned efforts in primary care e.g. e-learning module. Action: Network team to consider plan with midwifery leads • Workforce sustainability – registrars have little understanding/exposure to the network. How do we promote it to this group? Action: Network team to communicate with training programme directors (RB) • Research – there is a role for the network to promote research. Action: network team to consider plan • Pharmacists around the region are fielding queries. How do we cascade information to them? Need to talk to people in these areas as networks already exist – we need to tap into them. Action: network team to consider plan with pharmacy leads
3.	Promotion of the website and its resources for patients
	<ul style="list-style-type: none"> • Social media promotion • QR code and poster – both paper and electronic • Business cards/stickers for clinicians to give out • NB – Poster, leaflet and stickers are already in development by network team and copies will be offered to all centres. Action: Network team to communicate with teams when these are

¹ Patient Reported Experience Measure

	<p>ready</p> <ul style="list-style-type: none"> • Action: Network clinicians to put details of the website on their clinic letters • Could there be training for secretaries on the website and its resources – these are a group of key individuals who field queries from patients/families. Action: network team to consider plan • Role of charity partners and support groups in promoting the website – this has been requested already but continued support appreciated • Could CCGs share it with GPs? Post meeting note: the network will map CCG contacts in the future as do not currently have information on CCGs. • Could it be included in discharge communications to families e.g. in packs/booklets/leaflets?
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4.	Clinicians and managers forum
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	<p><u>Finance in Level 3 (L3) Centres in England:</u> Led by Geoff Shone, Head of Financial Management, NHS England South (See presentation for detail)</p> <ul style="list-style-type: none"> • Action: Network team to produce guidance for L3 centres in England on how funding works and what income they may be entitled to • Action: L3 centres in England to review their income and check if they are charging appropriately for the service being offered, or if there is scope to increase tariff but introducing a link nurse (MDT uplift). For discussion with finance/contract teams internally. Network team able to support. • Coding is important in this work. • Discussion of the future of PBR (payment by results) in England. Will there be a move to more block contract/activity bundle type models in future? • Who pays? NHS England pays for specialised commissioning, so Level 1 Consultants’ clinics will be paid for by them due to the consultant code, wherever clinics take place. • Consistency in coding would be helpful • Network team have raised the issues around funding at a national level and suggested a best practice tariff for CHD clinics undertaken in L3 centres. However, this is unlikely to happen quickly due to national picture on finances <p><u>Introduction to the specialist regional psychology service for CHD patients</u> Led by Dr Vanessa Garratt, Clinical Psychologist, University Hospitals Bristol (See presentation for detail)</p> <p><u>Dental care for patients with CHD</u> Led by Rosie Power, Specialist Paediatric Dentist (See presentation for detail)</p> <ul style="list-style-type: none"> • Piece of work required to map community dental services in the network • Need to understand what services exist locally and whether they are happy to review CHD patients • Pathway will be developed for CHD patients in the network: referral criteria for surgery should include a dental check-up prior to referral, as discovering dental problems at point of referral delays surgical pathway • Issues around access to dental care generally in Cornwall. Need equity of access. Action: NHS England colleagues to escalate issue to appropriate dental commissioners • What is the role of L2/L3 centres in dental care? • Repetition of messages by clinicians is important, information giving and someone to escalate to if dental care cannot be accessed • When is the right point in the pathway – neonatal is too soon, because families are likely to be overwhelmed and information will be forgotten by time the child has teeth • There is a national incentive to have all children dentally checked by 1 year
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	<ul style="list-style-type: none"> • Network wishes to develop/adopt existing pathways for adults and paedics in England and Wales • It is hard for general dentists to care for paediatric specialist patients – not many are able/comfortable to do so • Action: network dental champions to tap into national groups promoting this e.g. BSP website
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5. Patient representatives and charity partners forum
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<p>What is the ambition for PPI and the Network in 2021</p> <p>The Network has a reputation for collaborative working with patient, carer and charitable partner stakeholders. These stakeholders are seen as equal partners in the network and enjoy a dynamic relationship that fosters dialogue, trust and ideas sharing. Stakeholders describe themselves as ‘partners’ and can clearly demonstrate the impact they have.</p> <p>The features of this relationship include:</p> <p>Charitable partners</p> <ul style="list-style-type: none"> • Openly sharing intelligence and ideas both inside and outside of the network. This includes working across networks to foster wider relations and innovative practice • An alignment of priorities. A dialogue that enables partners to influence the priorities of the network and the network partners to influence the priorities of the charities. Aligning agreed joint priorities with fundraising initiatives • An overt recognition of the role of carers as partners in the network • A re-defining of the relationship charitable partners have on the board to acknowledge the wider influence and intelligence they have in addition to fundraising. This includes board development that explores the different cultures of partners and acknowledges the common and shared ground and, an enhanced focus and recognition of the research focus • Informed conversations built on a culture of transparency and willingness to do things differently <p>Patient partners</p> <ul style="list-style-type: none"> • An accessible, personable and trusted relationship with a higher profile • A process that gathers feedback from a wider patient cohort reaching different cultures across the network • process that is defined by collaboration where there is clear evidence of impact • A common language and understanding of the patient partners relationship <p>One thing that I wish to see:</p> <ul style="list-style-type: none"> • We want to work together as partners in the network • An investment in patients as leaders • A good governance process to recruit, support and grow patient partners at board level • Develop the use of social media as a tool for involvement without losing the emotional connect of face to face work • Disseminate knowledge, debate and discuss • Be engaged in the conversation • Get the simple things right and be aware that patient partners have other lives • Be able to say – ‘this wouldn’t have happened if it were not for patient partners’ <p>Next steps: a programme of work will be led by Sheena Vernon, Network Lead Nurse and Ness Garratt, Network Lead Psychologist, to develop and support patient representatives and charity</p>
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	partners					
6.	Evaluation form summary and post event feedback (AM sessions)					
	<i>Scale: 1 = very poor to 5 = very good</i>					
	Title	1	2	3	4	5
	The network two years on				11	11
	Patient representatives and charity partners forum					
	Introduction to the network				3	5
	Engagement guest speaker				3	6
	Network clinicians and managers forum					
	Regional psychology service				3	11
	Funding arrangements for L3 centres in England		1	2	7	7
	Dental care for patients with CHD			1	7	7
	Comments:					
	<ul style="list-style-type: none"> Funding not applicable to Wales Excellent opportunity to discuss finance Funding info very useful Not enough time I think each forum is equally important and therefore separating the two components was suboptimal Really useful morning – positive work re patient engagement/charity partners Very useful to be part of pt engagement work – informative 					
7.	CPD session feedback					
	Title	1	2	3	4	5
	The palliative care toolkit in a local setting			4	3	8
	Innovations in remote ACHD Cardiac Rehabilitation			1	5	9
	Delivering high quality transition and transfer care				7	8
	Developing the role of the PEC			8	5	2
	Spelling Tetralogy		1	1	9	4
	Fallot long term complications and interventions				3	10
	Paediatric drug protocols update				11	4
	The new genomics medicine service				2	9
	<ul style="list-style-type: none"> The afternoon was very rushed. It was excellent content, but perhaps too many sessions? I thought it was really interesting and so much interest that was generated we ran over but really good to share good practice and get involvement network-wide 					
8.	General feedback on event					
	<ul style="list-style-type: none"> Very useful Great networking event. Enjoyed CPD afternoon Well organised and the day did inspire and provide motivation to further improve to provide consistent streamlined approach across the network Very useful and informative, excellent networking opportunities Well organised thank you Very well organised, planned and executed Extremely helpful and a valuable introduction to the network I really enjoyed the event today, the group discussions were relevant (apart from the commissioning... but interesting) and I really enjoyed the afternoon format with multiple short 					

	<p>topics....</p> <ul style="list-style-type: none"> • You should be really proud of the network and what it stands for • Sessions over-running. Less topics to allow more discussion time? • Thank you for the opportunity to present. Great to know what's going on across the Network • Thank you. Very informative and useful meeting • Well done to all those who have been involved and pushed (nagged) to push forward and develop! • Thank you for all the hard work! • Very useful way to collaborate and investigate better ways of improving patient care • As new to the group, some acronyms could perhaps have been explained • Great event. A real energy in the room. I liked the balance between info giving and dialogue
8.	Frequency of future stakeholder days
	<ul style="list-style-type: none"> • 18/26 respondents would like the event held annually • 8/26 would like it every two years <p>Action: Network team to arrange a stakeholder event annually</p>

Attendee List:

Name		Job Title	Organisation
Arend	Andy	Consultant Paediatrician	North Devon Healthcare NHS Foundation Trust (Barnstaple)
Armstrong	Catherine	Consultant Cardiologist	University Hospitals of Bristol NHS Foundation Trust
Ashtekar	Sandeep	Consultant Paediatrician	Royal Gwent Hospital, Aneurin Bevan UHB
Barker	Dave	Trustee / Human Resources	Youth at Heart
Batcheler	Sandra	Nurse Educator	Faculty of Children's Nurse Education, Bristol Royal Hospital for Children
Bedair	Radwa	Consultant Cardiologist-Adult Congenital Heart Disease	University Hospitals of Bristol NHS Foundation Trust
Benefield	Rachel	Administrator	University Hospitals of Bristol NHS Foundation Trust
Carlin	Frankie	Patient Representative	
Curtis	Stephanie	Consultant Cardiologist	University Hospitals of Bristol NHS Foundation Trust
Edwards	Rhiannon	CVD Clinical Development Coordinator	British Heart Foundation
Evans	Caroline	Lead Cardiac Physiotherapist	University Hospitals of Bristol NHS Foundation Trust
Evans	Caryl	CNS	University Hospitals of Bristol NHS Foundation Trust
Finch	Sarah	ACHD CNS	University Hospital of Wales, Cardiff (Cardiff and Vale UHB)
Gage	Susie	Paediatric Cardiac Pharmacist	University Hospitals of Bristol NHS Foundation Trust
Garratt	Vanessa	Clinical Psychologist	CHD Network South Wales and South West
Giblin	Regina	CVD Clinical Development Coordinator	BHF
Gordon	Phil	Service Specialist	Specialised Commissioning - NHS England South (South West Hub)
Hayes	Alison	Consultant Cardiologist	University Hospitals of Bristol NHS Foundation Trust
Hennessey	Claire	Parent/Support Group	Max Appeal and SWCHC.
Hutchinson	Suzie	Chief Executive and Service Lead	LHM
Jermyn	Ann	Paediatric Cardiac nurse Specialist -Transition	University Hospital of Wales, Cardiff (Cardiff and Vale UHB)

Jones	Joanne	HPCP Registered Clinical Scientist, Paediatric and Fetal Cardiac Sonographer	University Hospitals of Bristol NHS Foundation Trust - St Michael's
Kennett	Trevor	Trustee / Administrator	Youth at Heart
Lambert	Becky	ACHD Nurse	Taunton and Somerset NHS Foundation Trust
Mabin	David	Consultant Paediatrician and CHD Network Chairperson	Royal Devon and Exeter NHS Foundation Trust
Macfarlane	Victoria	Deputy Divisional Director	University Hospitals of Bristol NHS Foundation Trust
Maddicks	Hilary	Consultant Paediatrician	Royal United Hospitals Bath NHS Foundation Trust
Mappa	Pradeesh	Paediatric Consultant	Great Western Hospitals NHS Foundation Trust (Swindon)
Morris	Nicola	Parent/Patient Representative	Heart Families South West
Moss	Caitlin	Network Manager	CHD Network South Wales and South West
Nash	Becky	Patient rep.	
Newbury-Ecob	Ruth	Consultant in Clinical Genetics	University Hospitals of Bristol NHS Foundation Trust
Padmanabhan	Sam	PEC	Royal Cornwall Hospitals NHS Trust
Patten	Lisa	CNS	University Hospitals of Bristol NHS Foundation Trust
Power	Rosie	Consultant in Paediatric Dentistry	University Hospitals of Bristol NHS Foundation Trust
Pullen	Kay	Matron, St Michael's Hospital	University Hospitals of Bristol NHS Foundation Trust
Reid	Joanna	Regional Programme of Care Manager Women and Children	Specialised Commissioning NHS South
Richards	Andrea	Specialised Services Planning Manager	Cwm Taf LHB Welsh Health Specialised Services Committee
Richardson	John	National Director	The Somerville Foundation
Shiers	Bethan	ACHD CNS	University Hospital of Wales, Cardiff (Cardiff and Vale UHB)
Shone	Geoff	Head of Financial Management – Specialised Commissioning South	NHS England – South
Stringfellow	Chris	Children's Heart Federation.	
Szantho	Greg	Consultant Cardiologist	University Hospital of Wales, Cardiff (Cardiff and Vale UHB)
Tometzki	Andy	Clinical Director	CHD Network South Wales and South West
Venkata	Nagendra	Consultant Paediatrician	Royal Devon and Exeter NHS Foundation Trust

Vernon	Sheena	Lead Nurse	CHD Network South Wales and South West
Wallis	Helen	Consultant Cardiologist	Abertawe Bro Morgannwg University Health Board
Wathen	Peter	General Manager	Gloucestershire Hospitals NHS Foundation Trust
Watkin	Tony	Patient and Public Involvement Lead	University Hospitals of Bristol NHS Foundation Trust
Wells	Lisa	Group Manager, Women's, Children's & Mental Health Interface	North Devon Healthcare NHS Trust
Wilson	Dirk	Consultant Cardiologist	University Hospital of Wales, Cardiff (Cardiff and Vale UHB)
Yarnell	Rosie	Service Specialist	Specialised Commissioning - NHS England South (South West Hub)
Yeong	Michael	Consultant Cardiologist	University Hospitals of Bristol NHS Foundation Trust

(53 in total)