Congenital Heart Disease Network South Wales and South West
Network Board Meeting

Date: **Tuesday 27 November 2018, 9.30 – 4.00pm**
Venue: **Coldra Court by Celtic Manor, Newport, NP18 2LX**
Chair: **Dr David Mabin**

Minutes

Item	Notes and Actions
1.	**Welcome, introductions and apologies**
	DM welcomed the attendees and noted apologies. CM offered condolences on behalf of the Network to Rod Walsh's family and friends after the sad news of his passing. CM updated the network board on recent personnel changes in the network team. CM has started a short notice secondment as Deputy Divisional Director with Women and Childrens division at Bristol Children's Hospital for the next few months and CMc will cover the network manager role during this time. CM also introduced MB who started her substantive role as network support manager in October. CM thanked Rachel Benefield who finished working for the network as administrator in summer 2018.
2.	**Approval of minutes and action tracker**
	The minutes of the Network Board meeting on 22 March 2018 were agreed as an accurate reflection of the meeting. CM explained that following the March board and the change to the network board structure some of the actions have been moved from the network board action tracker and assigned to either the clinical governance group or the service delivery group as appropriate. The action log was updated as appended. Notable comments: <u>Action number 28 – Access to UHW systems through Cardiobase</u> MB taking project forward. She has made initial contact with Cardiobase and now has an additional contact from DW. The network team is also supporting Cardiff with IPad software. DW questioned whether there had been progress with getting access to central systems, such as Heartsuite and Cardiobase, for peripheral centres. CM explained that there is not at the moment but there are projects the division are working on looking at information sharing, for example the network discharge communication project. A discussion was had about the use of different systems in adults and paediatric services. **Action:** Explore potential for peripheral centres to access to central systems, eg Heartsuite and Cardiobase **(AT/MB/CMc)** <u>Action number 62 – Telemedicine</u> Work to continue to raise the profile and opportunity for telemedicine. Funding is still available and centres are encouraged to identify both clinical and IT champions to take up the opportunity. CM explained it is accessible to any trust in the network and if interested they should speak to AT.

<u>Action number 63 – Palliative care toolkit</u>
Completed.
Action is signed off and closed.

<u>Action number 65 – Clinical risk assessment of backlogs</u>
Performance dashboard – support centres to address issues and backlogs. To Be discussed further in the afternoon session.

<u>Action number 66 – Paediatric protocols</u>
Protocols are needed ahead of the peer review and for NHSE by the end of March. Work is in progress to complete these.

<u>Action number 67 – Centres to consider audit opportunities</u>
Allocated to clinical governance group. Each service in network is required by the standards to undertake one audit per year.

<u>Action number 68 – Grace's story video on website</u>
CM informed the board that the video is now on website and that a CHD Network youtube channel has been set up to facilitate videos going on website. CM explained there is also an opportunity for staff stories to go on the website in the professional section.

Action: Discuss with patient reps whether they would like to share their story on the website **(MB**)

<u>Action number 69 – Website details on clinician letters</u>
There is a concern that the information and details about the CHD Network website is not being widely shared with people. The network team have produced three posters (an adult and child version, an infographic about the network) and an information leaflet to promote the website and its content. The team has also produced small coloured stickers with the website address and twitter handle on that can be used on letters etc. The posters, information leaflets, and stickers will be sent out to centres shortly to help with the promotion of the website and to increase the numbers of patients and their families accessing it. It was noted that everyone needs to support advertising the website. CM asked for ideas to promote the resource. A discussion was had about the use of twitter, Facebook and using the UH Bristol Facebook and communications teams in other centres to promote the website. DW raised a point about moderating content.

Action: Explore whether Heart Families South West (charity) could help promote the network website. **(CMc)**

Action: Send out resources for advertising the website to centres. **(MB)**

Action: Make sure website address is in letter template for Bristol and peripheral clinics. **(VM)**

3. New network governance structure and role of the network board
Stakeholder Day report

CM explained the new network board structure and sub groups. The network board, clinical governance group and the service delivery group will each meet twice per year, so 6 meetings per year in total. The network board is the oversight and assurance group and includes key leads from level 1 and level 2 centres plus representatives from level 3 centres, patient reps and commissioners. It was explained that the aim of the new structure is for more active participation and to set direction with the aim of members attending two meetings per year consistently to make meetings more interactive. The board was asked for any comments. There was a formal decision by the board to support the new structure.

A discussion was had regarding chairing of the subgroup meetings and what the mechanism would be for reporting into the network board. CM explained that the minutes are shared, the overall work plan can be reported to the board and the network team who will report back to the board. She clarified a separate chairperson would be needed for each of the three groups. It was discussed that reporting back from these subgroups to the board and to commissioners was important. CM confirmed that the expectation would be for a nominated member of the subgroup to report back and update the Network board on progress within the subgroup and escalate any risks or issues as required. Each group will have an individual action tracker. The minutes of each of the groups will be shared with the board as well as being published on the website so they will be publically available. It was identified that the mechanism for reporting into the network board, in addition to provision of the minutes, by the sub- groups will need to be confirmed.

Action: Add in agenda item for chairperson tenure for network board and sub groups. **(MB)**

Action: Circulate the membership details of each of the groups in the new structure. **(MB)**

The terms of reference were sent out with the papers for the meeting. Any comments were requested so that they could be signed off at the meeting. It was explained that there is one combined terms of reference for the three groups. CM talked through the terms of reference document.

Action: Terms of reference to be updated to include chairpersonship, responsibility of sub groups to report and escalation to network board, and review of structure at 12 months, and then circulated to the board for final sign off. **(CMc)**

A question was raised by RY about how NHSE quarterly review fits into the network governance and whether some duplication of assurance meetings could be avoided.

Action: Review NHSE quarterly review meeting and Network Board meeting for duplication and agree requirements going forward. **(CMc/RY)**

The minutes of the clinical governance group were shared and it was noted that the clinical governance group and M&M meeting were well attended.

Stakeholder event

The board was informed that the feedback from the stakeholder event evaluation report showed that most respondents would like one stakeholder meeting per year. The stakeholder day is open to anyone in the network and includes open focus sessions.

4. Items in the network work plan for the Network Board

CMc highlighted the actions remaining on the work plan for the Network Board. The other actions have been allocated to the service delivery group and clinical governance group. The network board has 16 actions assigned.

Two actions are overdue: 1a) Self-assessment follow-up and 1b) Commitment from Trusts/Memorandum of Understanding. Letters will be sent to centres, which summarise where the centre is against the standards. A point was raised about Welsh Specialised Services supporting delivery of this action for centres in Wales.

Action: Link with Andrea Richards to support this action for Wales. **(CMc/MB)**

One action recorded as not yet started: 1f) Level 3 centres. This was covered later in the agenda in updates.

A brief discussion was had about increasing the engagement with level 3 centres which included participating in active work level 3 peer review, opportunity for hub and spoke working, challenges with engaging adult consultants, job planning pressures, adult equivalent of PEC day, and challenges with level 3 link nurse engagement. CM has spoken to new managers so that they understand the network.

Action: Change work plan action 1f) Level 3 centres status from red to amber status to reflect work is in progress. **(MB)**

The expansion of Bristol Royal Hospital for Children was briefly mentioned by CM. This would be a major capital project for implementation over the next few years, if supported by the trust, to expand the BRHC including the Paediatric Intensive Care Unit.

The other actions were either on the agenda later in the meeting or are ongoing and weren't discussed.

There was a discussion around the NHS Peer Review and Wales. AR confirmed that WHSSC are aware of the NHSE peer review. CM explained that it is expected that Cardiff will be included in the peer review. CM noted that the Quality Surveillance Team (QST), who conduct the Peer Review, have sent out draft peer review quality indicators for teams to review and feedback on before the end of November. This is an opportunity for teams to raise any potential issues or points requiring clarification on the quality indicators in advance of the Peer Review. These quality indicators have been sent out to the clinician teams by the Network team to feedback on to the QST team.

5. Network research strategy/programme

The board were informed that one of the CHD standards requires a network research strategy and programme of research activities to be in place. All of the research activities that the network is aware of have been collated into the research programme which was circulated with the papers and discussed by the board. It was noted however that an overarching network research strategy was not yet in place and that a discussion by the board about this, and an agreement about what is needed to fulfil the standard, would be helpful.

KS updated the board on a number of research activities that are happening within the region, which are outlined in the research paper, and also informed the board that UH Bristol has a generic research strategy, that is currently being rewritten. She also noted there is a National Institute for Health Research (NIHR) nursing strategy. There was a query about whether the research studies noted in the paper were regional or just specific to Bristol. KS explained that patients have been recruited from all areas across South Wales and the South West for research. She noted how adult research does less specific congenital work and it is under more generic cardiac/cardiovascular work.

CM noted that she had contacted Professor Williams about research in Exeter however this work is not currently captured in the strategy. It has been agreed the network team will contact Professor Williams every 6 months to see if there are any updates for the research programme document.

It was noted that research updates are put in the quarterly network newsletter. It was identified that a mechanism to understand and record research that's happening peripherally would be helpful whilst acknowledging that this may be challenging to achieve.

DM acknowledged that the network meets some of the standards related to research. It was questioned whether strategy is the right word for the network to use as it was not realistic that the network would be able to have a current and relevant network strategy for research. CM explained there is a network programme of research activities, which is not exhaustive but does capture the main pieces of work, and that a strategy could be developed for the network which signposts to existing research strategies both nationally and across the network. DM supported this and added that the work has to be done through existing research structures and the strategy has to be drawing together of what is already in existence. CM noted that the network could act as a central point for patients to understand research and to sign post them as required. A question was raised as to whether any research was happening in Wales or in the peripheral centres that may not be included in the programme. It was suggested that the network would struggle to meet the section of the standard that 'all centres should participate'. KS emphasised that all patients in the level 1 centre in Bristol participate which covers wide areas, for example inpatient research as well as drug trial follow ups in the community. DM commented that it is difficult to meet the standard that all centres participate in research but that they can support research studies by having their patients participating in them. KS noted that the research in Bristol covers the whole of South West and added that the Bristol Heart Institute is asking every surgical patient about participating in a current research trial.

CM thanked KS for her all her continued hard work and support.

Action: Use the standards to determine objectives for research including and develop network research strategy that signposts to other existing research strategies in the network. **(SV)**

Action: Update the programme of research activity with any further details of research as and when required **(SV)**

Action: Ensure links are made to Cardiff adult research nurses to include any detail in the research strategy as applicable. **(SV)**

6. Update from L3 centre(s)

DM gave the update to the board for the level 3 centres. He outlined difficulties in adult services in relation to capacity and staffing, with significant waits for access to services and challenges with paediatric image storing in Truro. He announced the new PEC in Taunton, Gangadhara Bharmappanavara. DM noted the key role of the link nurse in supporting the level 3 services.

DW gave updates for level 3 centres in South Wales. He highlighted a risk of delays in care provision in Singleton due to a sonographer with a key role in paediatric echo retiring shortly. He updated that Morriston hospital has a new echo machine and that The Princess of Wales Bridgend have no particular issues to report. He noted issues around the 52 weeks waiting time for adult services in Abertawe Bro Morgannwg, image transfer issues, and waiting list pressures in all health boards.

The board was asked whether they would like to invite level 3 representatives on rolling programme to present at the network board however it was noted that it would be more beneficial if level 3 centres were actively engaged in the other subgroups to help support and resolve issues, which could be escalated to the network board as required.

	Action: Include a description of how the level 3 centres would report to the network board in the Terms of Reference. **(CMc)**
7.	Update from L2 centre
	DW gave the update for the Level 2 centre (University Hospital of Wales, Cardiff). He noted that there was an advert in the BMJ for a new consultant and that in adult services Clive Wilson, adult cardiologist, is retiring. In terms of facilities, Cardiobase is now accessible for the different health boards, and extra paediatric clinics are being held across the patch. DW highlighted that a Welsh audit day will be held on 22nd January at University Hospital Wales. There will be a Bristol and Cardiff consultant away day on the 4th March, focussing on communication and strategic planning. DW explained that the recent Welsh Paediatric Cardiovascular Network day had positive feedback. The next meeting is April 12th and the theme is CVS therapeutics and treatments with the main purpose being education. The Aim study day was completed and is being written up. DW noted there were no new risks to report and that risks would be covered later in the agenda. **Action:** Upload the programme for the Bristol and Cardiff consultant away day on 4th March onto website and circulate via email. **(MB)** SF highlighted the link nurse half day in Cardiff on Friday 30th November. The aim of the meeting is to improve communication around ACHD with the ward nurses in University Hospital Wales. The plan is for this meeting to occur every few months.
8.	Update from L1 Centre
	VM gave the paediatric update for the Level 1 centre (University Hospital Bristol). VM explained that the surgical waiting list is fluctuating at the 60-70 mark which is an improvement on a few months ago when the surgical waiting list was over 100 patients. VM confirmed that the joint cardiac conference (JCC) keep track and validate patients after cancelations. Currently Cath lab waiting times are slighter higher than desired. Cecilia Gonzalez has been recruited into a consultant cardiologist position. There is a plan to increase the provision of fetal screening to address current backlog issues and an advert is out to recruit a locum fetal consultant to cover maternity leave. VM noted that the cardiac MRI waiting list is increasing due to an increase in demand and work to provide more paediatric MRI capacity in the New Year is underway. The cardiology clinic wait time has improved with new clinics planned for South Bristol. The Weston clinic will be embedded which will improve services for new patients and for follow up. VM discussed the Higher Specialist Scientific Training (HSST) programme with one trainee already 2 years into the 5 year programme and another member of staff is keen to get onto the programme. This will help with a longer term strategic plan for physiologists. **Action:** To understand whether the HSST training programme offers any wider benefits for the network as a whole in addition to the Level 1 centre. **(CMc/VM)** There was a discussion about the pivotal role of the physiologist in the patient pathway and how it is a current concern. CM queried whether physiology should be part of the networks work plan for next year. **Action:** Discuss AHP representation on network board/service delivery group with clinical leads. **(SV)**

It was highlighted that the initial paediatric protocols, which RT has drafted, have been circulated internally for feedback, following this they will be shared with level 2 and level 3 centres for further comment before they are finally send out.

SV gave an update on behalf of adult services for the Level 1 centre (University Hospital Bristol). Key updates and risks were summarised from the exception report. SV highlighted that the centre is working on producing same day clinic letters. There has been a recent Bristol and Cardiff ACHD Echo course and South West ACHD Nurse study day which were both positively received. The team continue with their audits. Clinical protocols have been updated in November 2018 and are now on the website. Graham Stuart is retiring and a locum consultant has been appointed. In terms of risks SV highlighted that there are ongoing discussions relating to ECMO and interventional numbers. SV explained that Steph Curtis is stepping down as clinical lead and Radwa Bedair is taking over. CM gave a formal thank you from the network to Steph Curtis for all her commitment and hard work.

9. Commissioner updates:

- WHSSC (Phase II update)
- NHS England (Circular and forthcoming peer review process, Quality Indicators Consultation)

AR gave an update on behalf of WHSCC explaining that planning for 2019-21 has started. She updated on Phase II, explaining that a business case had been submitted for prioritisation with health boards. The business case was presented on the 9th November to commissioners and scored highly in the clinical risk and impact assessment. She explained that the funding from Welsh government will be dependent on the scoring from the assessment and therefore what the board decides to invest in.

RY gave the NHSE update. She went through an update from VL which highlighted: The CHD Network continues to focus level 1 and level 2 compliance with the key standards and NHSE are working closely with Bristol to achieve the standards. The CHD network meets quarterly to review the NICOR data and the quality dashboards. The Welsh level 2 centre adult activity is lower than the English standards expect, so is not fully compliant. There are still some issues to resolve in relation to Interventional Cardiology activity levels. Consideration is still needed for a 4th Surgeon. The Welsh health board has not formally adopted the CHD standards. The level 3 services are all CCG funded, but remain an important part of the network. NHSE and NHSI are currently out to consultation on a new operational model, but this is unlikely to impact on the CHD network.

The board were informed about the peer review which will go ahead in May/June 2019, specific dates have not yet been given. The network, and in particular the clinical team, have been invited to comment on the peer review quality indicators which will be used in the peer review and to give feedback to the Quality Surveillance team by the end of November. The Quality Surveillance team will conduct the peer review. Following the peer review a report will be produced with recommendations. CM confirmed that the network team will share information on the peer review as they get it. The quality indicators are based on the standards. If there are any comments on the indicators let CMc know by the end of November

Action: Clinical Team to give feedback on quality indicators to Quality Surveillance Team by end of November as per email sent by CM and CMc previously.

10. Network performance:

- Network performance dashboard
- NHS England quality dashboards
- Patient Reported Experience Measure (PREMs) survey

Network performance dashboard

CMc went through the network performance dashboards. It was noted that both adult and paediatric response rates had improved since the last submission in March. There were 9 adult responses and 11 paediatric responses. Hotspots were identified which are highlighted on the dashboard report.

Text reminders were highlighted as a possibility to reduce DNA rates. SF highlighted that this has started in Cardiff. It was noted that for the inpatient dashboard a query had been sent to SC for clarification of the data. CM highlighted that some centres don't reply which makes it hard to have a picture of what is going on. A question was proposed asking what the board can do as well as commissioners if there are performance issues highlighted. It was flagged that the network has no formal lever in terms of managing performance but that each centre should have local performance management systems that are monitoring and improving performance.

There was further discussion on the dashboards in the afternoon focus session; "Patient access and waiting times".

NHS England quality dashboards

It was explained that NHSE quality surveillance systems are in place for specialist contracts which covers annual performance, peer review and the Specialised Services Quality Dashboards (SSQD). The SSQD is produced quarterly using retrospective data and gives a national picture of performance against key quality criteria. The data is presented as a bar chart and shows where the service is performing on a scale. Three key issues were reported from the paediatric dashboard;

- **CHO3:** adequate information provided at discharge. CM explained that the denominator used in the results is from the PREMs Survey which has a very small sample size therefore reducing the validity of the results.
- **CHO5:** proportion of patients with suspected CHD seen within 3 calendar days of sonographic identification. VM explained that the fetal services are struggling with cardiologist cover but a sonographer has been appointed enabling parallel screening services which will help improve performance against this measure and it was noted that the 3 days included weekends making it a difficult standard to meet without a 7 day service being in place.
- **CHO6:** proportion of patients with confirmed diagnosis of fetal congenital heart disease contacted by fetal cardiac nurse specialist on day of diagnosis. It was noted that staffing due to maternity leave had made it difficult to meet this standard however there is now a rota in place with cover over 5 days. No issues have been escalated to VM so it is expected that this measure will improve in the next quarter.
- **CHO10:** Last minute cancelations of elective surgery procedures for non-clinical reasons, was highlighted as the result has improved. However it still remains a key focus area as it has a significant impact on patients and the clinical team.

The network board is responsible for being aware of the issues highlighted in the dashboard reports and knowing what plans are in place to help resolve these issues in the next quarter. The data is retrospective therefore it could have changed by the time the report is published. Overall the dashboards show a positive picture. There were no issues with adult services.

PREMs survey

The national patient report experience (PREM) survey is set up by NHSE. Currently it includes the level 1 centre only but there is scope for a discussion about inclusion of level 2 centres. CM explained that the data presented is at a national level and therefore less meaningful. One detailed report per year is provided on patient feedback. The survey currently has a low response rate, in quarter 1 there were 40 responses and in quarter 2 there were 13 responses in Bristol. It was noted that patients are asked to fill out a lot of forms and questionnaires. Some areas have adopted a “one month per year” push to fill it out in clinics. Other suggestions included volunteers, twitter, text messages and the website to try to get a higher response rate. It was highlighted that Southampton had the highest number of responses by using a nurse in clinic. The patient reps were not aware of the survey.

Action: Raise profile and aim to increase responses for PREM survey. **(SV)**

Action: Patient reps to look at PREMs survey from an ease of use perspective and feedback. **(FC/BN)**

11. Network risks

The Network board is responsible for oversight and assurance of risks and mitigations.
There are currently 7 open risks on the network risk register – 2 have been closed since the last Network Board meeting in March.

Risk 2204: Risk that network centres will be unable to identify or fund link nurses, reducing quality of service to patients. This was discussed later in the day.
Risk 2191: Risk to long term sustainability of CHD care in region due to the lack of medical workforce in future/lack of succession plans. There has been engagement with Health Education England (HEE) at a meeting, medical training is aware of workforce issues in specialities and there are plans in place but these are not reassuring. There is a good training programme but there are issues with staff staying in roles in the NHS. A discussion was had around promoting sub speciality roles and what the network should be doing. It was highlighted that the roles are less attractive, the routes into ACHD have changed and there is no longer a way to move from paediatric to adult. To mitigate the risk local centres are raising specific acute issues with their boards as required. Keep risk on register.
Risk 2363: Risk of cancelled paediatric cardiac ops due to PICU capacity pressures. There is a long term strategy for expansion at BRHC. Operations which are cancelled for a third time have to go to the clinical director for sign off and therefore only happen if absolutely unpreventable. There are particularly issues during winter. The board and the network team are supporting the expansion case. Mitigations include clinical assessment, decisions to cancel required senior clinical authorisation, and patients who are cancelled are rebooked and tracked. Keep on register.
Risk 2495: Risk of inferior care being provided to patients in some parts of South Wales due to inequitable investment in services. There is a tentatively positive update related to Phase II. The risk is mitigated as basic service provision is in place. Keep on register.
Risk 2748: Risk of not meeting the standard for care around interventional cardiologist case numbers. In discussion with level 1 and Wales around numbers and what is possible, which will be reported to NHSE in December. Keep on register.
Risk 2916: Risk of delay in clinical care due to image sharing between organisations in the network. A number of actions and mitigations have been covered previously in the meeting. Keep on register.
Risk 2915: Risk of challenges with provision of fetal cardiology screening at UHBristol within a clinically acceptable timeframe. Actions have been discussed. Reassess at next network board meeting. Keep on register.
Risk 2304 and 2214 closed.
It was noted that other risks are highlighted from the network dashboards. Some centres are unable to get the data such as Gloucester, and some have to manually get the figures such as Taunton.

The board were asked to highlight anything that was missing from the risk register.

AR highlighted the paediatric waiting times in Hywel Dda UHB of 18 months due to problems with access to PEC clinics. DW highlighted transfer issues which were discussed.

Action: Develop transfer and repatriation policy for the network. **(SV/AT)**

12.	AOB
	The Network was very sad to hear about unexpected death of Said Hussein Amiri on July 11th 2018. Said was a keen and motivated patient representative and was continuously championing improvement in care and services for all patients with congenital heart disease. Despite his complex heart condition he made a significant contribution to the Network and was ready to attend meetings, offer an opinion and ask the difficult questions on behalf of patients. He will be a loss to the congenital heart disease network and will be greatly missed. The next network board meeting has been provisionally booked for 21st May 2019 – venue tbc. The next meeting is the Service Development Group on 18th January 2019 in Bristol – Holiday Inn Bristol Filton, Filton Road, Bristol, BS16 1QX.

Comments and actions from afternoon focus sessions

Item	**Notes and Actions**
1.	**Empowering our patient representatives**
	SV gave a presentation explaining the standards relating to patient engagement; the background and context to the role of patient representative, progress to date, outputs from the stakeholder day, challenges, and feedback from the patient representative's day (see slides for detail). FC and BN, the network patient representatives introduced themselves and told their stories. FC and BN explained the themes from the patient representatives' day in November and talked through the discussions that were had. **Action:** Minimise use of acronyms where possible to ensure clear user friendly information is being provided. **(All)** The board was asked their top three priorities for patient representatives for the next 12 months. Feedback included; Patient representatives attend all three network groups, feedback on anything public facing (for eg. website, information sheets etc.), involvement in projects, feedback on local processes, act as liaison between patients and their families and hospitals, signposting as required to appropriate resources, recruitment of new patient representatives using the website, parent groups, national groups, clinic etc., and succession planning. It was concluded that patient representatives should be embedded at every level of the network. The role and person specification was included in the papers and feedback was requested. **Action:** Implement the feedback on the role of the patient reps**. (SV)** **Action:** Finalise the Job description and use it to recruit more patient reps (10-15). **(SV)** **Action:** Draft engagement programme for patient reps for the next year. **(SV)**
2.	**Network Nursing Strategy**
	SV gave a presentation explaining the standards relating to the link nurse role, the background and a progress update on establishing the role in the network centres, the key objectives, the current situation, successes and challenges, the nursing strategy and job description for the role (See slides for detail). BL explained how they have implemented the link nurse role in Taunton. SV noted that a survey has been conducted to gather information on the current progress with link nurses

involvement in their local service.
Action: Link nurse survey results to be added as an agenda item at the next service delivery group on 18 January 2019. **(MB)**

Action: Ongoing work to engage with link nurses. **(SV)**

The network nursing strategy was shared with the board for comment.
Action: Feedback on the nursing strategy by the 4th December before it is finalised and circulated to the network (All)

3. Patient access and waiting times

DW raised some key questions related to the dashboards for discussion by the board.

1. **Are we asking the right questions? It is useful and meaningful?**

It was agreed that the wait times for new patients are useful however the wait times for visiting specialist is trust/hospital specific. For example, 6wks might be the next clinic but if a patient needs to be seen urgently then they will be seen. Delay for local consultant is useful, but there is a question as to whether it is clinically significant. The difference between the time the patient was intended to be seen and the time they were actually seen is more important. A distribution chart showing if the number is just past or further past the intended time as well as the clinical significance would be better. Also looking at whether the patient has come to any harm or has there been a significant change that should have been seen would be helpful. However, there is no information system which is designed to capture this type of information. It was questioned whether the network board should be involved and was explained that if there is systemic problems to patients the hospital/trust should be aware as well as the network. It was noted that DNA rates are linked to social deprivation association which is a wider issue. Reminder systems were mentioned and it was highlighted that issues could be due to systemic processes.

2. Are there other questions we should be asking?

There isn't other information that is easily accessible through data systems but could be collected through audit or audit could supplement the data. Examples suggested included looking at when a patient is seen and when letters are sent. Developing a common audit tool and an audit of clinical appropriateness was proposed. It was noted that routine patients are seen within 6 weeks, and urgent patients are seen within 3-4 months. Intra hospital comparators or comparing within the trust per year were highlighted as options. It was noted it would be harder to do for visiting clinics and audit of appropriateness to tertiary specialist is more important than length of time. Overall, the questions are right but could be supplemented.

3. Is the data correct?

It was explained that some hospitals can't get the data. For example Taunton has to manually get the data. Questions asked included; Are we asking same questions? Are we getting same answers? Is the data reliable? Are we fairly comparing different areas? It was highlighted that a presumption has to made that the information provided is correct and the data should be explained as 'according to the information you provided us'.

4. How can the data bring about change?

It was highlighted that the data is only useful if it is being acted on. Other questions related to this included; Are they enhancing patient care? What escalation processes are in place?

5. How can we improve response rate? Are we missing data?

6. What is a reasonable time past review?

It was questioned how long after a review date the patient is not happy if it hasn’t been followed up. Do clinicians have the same follow up times? It was noted that there may be particular areas where there are follow up issues. The network board role when the data is red was questioned.

It was agreed that the dashboard information should continue to be collected be quarterly. It was suggested that if an area had two subsequent quarters of red data then some follow up action by the board should happen, with possibly a visit or letter. A discussion was had around needing acceptable tolerances for each measure, what tolerances escalate an issue, red/amber/green needs defining and validating for each measure. The way DNA rates are measured was mentioned.

Action: Performance dashboard to be added as a standing agenda item for the service delivery group. **(MB)**

Action: Draft parameters for performance dashboard to be developed and presented at next service delivery group for agreement. Agree how performance dashboards are to be used to improve performance across the network and report back into the network board. **(CMc/DW)**

It was highlighted that the dashboards are published on the network website and questioned whether they were sent out to centres following presentation at the board. It was agreed that an email should be sent to centres explaining that the dashboard was presented at the board, allowing any queries to be raised, and giving notice that it will be published on the website. It can be noted if the centre cannot provide the data.

Action: Email to acknowledge receipt of the dashboard and inform leads that the dashboards are now available on the Network website. **(MB)**

Attendees

Name	Inits.	Job Title	Organisation
Cat McElvaney	CMc	CHD Network Manager	CHD Network Team
Sheena Vernon	SV	CHD Network Lead Nurse	CHD Network Team
Morwenna Bugg	MB	CHD Network Support Manager	CHD Network Team
Caitlin Moss	CM	CHD Network Manager	CHD Network Team
Frankie Carlin	FC	Patient Representative	
Sarah Finch	SF	ACHD specialist nurse	University Hospital of Wales
Rebecca Lambert	RL	Staff Nurse ACHD	Taunton and Somerset NHS Foundation Trust
David Mabin	DM	Consultant Paediatrician with Expertise in Cardiology and Network Board Chair	Royal Devon and Exeter NHS Foundation Trust
Victoria MacFarlane	VM	Deputy Divisional Director, Women's and Children's Division	University Hospitals Bristol NHS Foundation Trust
Becky Nash	BN	Patient Representative	
Andrea Richards	AR	Specialised Services Planning Manager	Cwm Taf LHB Welsh Health Specialised Services Committee
Karen Sheehan	KS	Paediatric Cardiac Research Sister	University Hospitals Bristol NHS Foundation Trust
Lucy Stacey	LS	Clinical Leadership Fellow	Cwm Taf LHB Welsh Health Specialised Services Committee
Dirk Wilson	DW	Consultant Paediatric Cardiologist	University Hospital of Wales
Rosie Yarnall	RY	Service Specialist	Specialised Commissioning NHS England South West Hub

Apologies

Name	Inits.	Job title	Organisation
Andy Tometzki	AT	CHD Network Clinical Director / Consultant Paediatric Cardiologist	CHD Network Team
Vanessa Garratt	VG	CHD Network Clinical Psychologist	CHD Network Team
Soha Elbehery	SE	PEC / Consultant Paediatrician	Nevill Hall Hospital, Aneurin Bevan University Health Board
Stephanie Curtis	SC	Consultant cardiologist	University Hospitals Bristol NHS Foundation Trust
Manish Gandhi	MG	Consultant cardiologist	Royal Devon and Exeter NHS Foundation Trust
Vaughan Lewis	VL	Medical Director Specialised Commissioner NHS South	Specialised Commissioning NHS South
Rachel Tidcombe	RTi	Patient Representative	
Rob Tulloh	RT	Consultant paediatric cardiologist	University Hospitals Bristol NHS Foundation Trust
Nicola Morris	NM		Patient Representative
Sam Padmanabhan	SP	Consultant Paediatrician with Expertise in Cardiology	Royal Cornwall Hospitals NHS Trust
Gina Skipwith	GS	Women's and Children's Operational Manager	Torbay and South Devon NHS Foundation Trust