



South Wales and South West
**Congenital Heart
Disease Network**

CHD Network Board

Tuesday 7th December 2021

14:00 – 16:30

Chair: Dr Dirk Wilson



14:00

Welcome and thank you for joining the meeting!

Conference call arrangements



Please can all participants **go on mute unless speaking** / presenting, to help reduce background noise.



Please **keep cameras on** if possible, to help support engagement and discussion



Please use the **MS Teams 'hands up' or 'chat'** facility to make live comments or ask live questions



Please note that this call is being recorded

Thank you

Item 1: Welcome and introductions



Introduce

- Steven Pike, Interim General Manager at Bristol Royal Hospital for Children (covering Rosalie's leave)



Board photo for the network website and social media



Board feedback form – please take the time to provide your feedback at the end of the meeting:

<https://forms.office.com/r/FG2hv77cJK>

Item 2: Minutes from the last meeting 16-09-2021

- Please refer to the minutes (in the papers)

14:05 2.2 Action tracker from the last meeting (16-09-2021)

| Meeting date | Action number | | Person Responsible | Due Date | Status Update | Closed |
|--------------|---------------|---|--------------------|----------|---|--------|
| 09/03/2021 | 161 | To review Exeter ACHD data and Plymouth ACHD data, and liaise with Exeter/Plymouth ACHD service about waiting list issues and how can support with this. | CME / AT | Jun-21 | Corresponded with Exeter ACHD Lead and Plymouth ACHD Lead. | Close |
| 09/06/2021 | 164 | Formal letter to be sent to centres that are not reporting performance quarterly data to the network board. | JM/AT | Dec-21 | Have been discussing with centres individually. Formal letter is still required. | |
| 16/09/2021 | 166 | AT agreed to send a letter of support to Truro to support the business case. KH to provide availability so a meeting can be arranged to discuss what is needed. | KH/AT | Oct-21 | Completed and letter sent. | Close |
| 16/09/2021 | 167 | Quarterly performance data requests - Centres to let RB know if they have a data analyst they would like to be included in the data requests. | All | Nov-21 | Ongoing. This has proved helpful for centres who have taken up the offer. | Close |
| 16/09/2021 | 168 | Rosalie Davies (or representative) to feedback on the BRHC pilot project on DNA rates at the next meeting. | RD/SP | Mar-22 | Project started in October 2021. Update to be provided at March 2022 Network Board. | |

14:10

Item 3 – Patient Story

December 2021



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Amia's story.

Pulmonary Atresia (Fallot type), VSD, ASD, Left – sided SVC in unroofed coronary sinus.

<https://www.swswchd.co.uk/en/page/amia-s-story-6>



The beginning.



Week 1.



OHS 1.



Next.



Now.



Patient Story – For discussion

- Are there any learning points for the network/network centres?
- Are there any actions that could be taken?

14:25

Item 4: Performance dashboard

December 2021

Please refer to paper ; 4.1 CHD Network Performance Report Q2



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Item 4.2: NHS England SSQD dashboards

NB// Please refer to the reports in the papers for detail

| CHD Centre | Negative | Positive | Neutral |
|------------------------|---|--|---------|
| Adult Level 1 CHD | 1 (30-day re-intervention rate following primary catheter intervention procedures) | 1 (Hospital Acquired MRSA: Proportion of inpatients under care of the adult congenital cardiac service acquiring new positive MRSA cultures) | 0 |
| Paediatric Level 1 CHD | 0 | 1 (30-day re-intervention rate following primary catheter intervention procedures) | 0 |

Item 4.3: Surgical performance update

14:35

Item 5 - Network Centre updates (by exception)

December 2021



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Level 3 Adults – South West

Key Updates

Plymouth, Derriford Hospital

- Dr Chicote-Hughes has provided additional lists in both September and October 2021, and this has improved our backlog position.
- Also looked to offer a vacancy for Clinical Fellow in Adult ACHD, outcome TBC.

Taunton, Musgrove Park Hospital

- All patients now being seen face to face, unless they request otherwise

Risks / Concerns to be escalated

Truro, Royal Cornwall Hospital

- Ongoing difficulties keeping on top of outpatient waiting list backlog.

Gloucestershire, Gloucester Hospitals

- Part-time Specialist Nurse has had to mainly withdraw from support of the ACHD to support the Rapid Access Chest Pain Clinic. The level of support provided for the ACHD service has thus declined further with this loss.

November update: A new Matron, covering the Cardiology Service, started in November 2021 (after several months vacancy gap) and is due to meet with specialist nurse to discuss this issue.

Actions / Support required from network

Truro, Royal Cornwall Hospital

- Increasing workload and need for ACHD Nurse support

Level 3 Adults – South Wales

Key Updates

Hywel Dda UHB, Glangwilli Hospital

- Now have a local cardiologist supporting the clinic, so hopefully this will start to have a positive impact on the waiting times.

Cwm Taf Morgannwg UHB, Princess of Wales Hospital

- Return of face to face clinics.
- 0% DNA rate this quarter is a combination of telephone clinics and the first face to face clinic which was booked with patients who had contacted the team with clinical concerns.

Swansea Bay UHB, Morriston Hospital

- Extensive validation undertaken during the previous reporting period - several patients were referred back to other centres (Carmarthen and Bridgend) and referred on to normal adult services, a small number had also been removed as a result due to moving out of area (England)

Risks / Concerns to be escalated

Hywel Dda UHB, Glangwilli Hospital

- Still significant waiting times, but hopefully there will be an improvement going forward.
- DNA rate is still concerning, and it has been asked if text reminders can be sent out - awaiting to hear if this is possible.

Cwm Taf Morgannwg UHB, Princess of Wales Hospital

- There is still no local cardiologist supporting the clinic, so all clinics are running at 50% capacity, hence negatively impacting waiting times.

Swansea Bay UHB, Morriston Hospital

- Following the resignation of Dr Weston (SBUHB Lead for ACHD) in 2018, a replacement has not been appointed.
- No formal SBUHB lead for ACHD, Dr Heatley is covering this work. Management is fully aware.

Actions / Support required from network

Cwm Taf Morgannwg UHB, Prince Charles Hospital

- Ownership of patients with suspected or actual cardiac disease in CTUHB aged 16/17 years still needs to be resolved satisfactorily.

Cwm Taf Morgannwg UHB, Princess of Wales Hospital

- Support the need to recruit a local cardiologist with an interest.

Swansea Bay UHB, Morriston Hospital

- Encourage SBUHB to formally appoint a replacement for Dr Weston with an interest in ACHD

Level 2 (Cardiff) Adults

Verbal update to be provided

Key Updates

Risks / Concerns to be escalated

Actions / Support required from network

Level 1 (Bristol) Adults- Dr Greg Szanths

Key Updates

- 3 WTE ACHD CNSs in post - still 2 short.
- Admin staff now complete.
- Dr Simon MacDonald (Cardiff) contributes now to the ACHD on-call service.

Risks / Concerns to be escalated

- None noted.

Actions / Support required from network

- None noted.

Level 3 Paeds – South West

Key Updates

Exeter, Royal Devon and Exeter Hospital

- Paediatric cardiology services continue to offer all levels of provision with no restrictions to urgent work.
- Waiting lists are being prospectively managed and ways of addressing this are being looked into (additional PA allocation, generating ring-fenced ICC work, pilot of paediatric cardiology physiologist led clinic).
- Further guideline development and ratification (acute SVT, Exercise test etc).
- Future work looking at our transition model and link nursing areas are ongoing.

Gloucester, Gloucestershire Hospital

- Continuing to make the case for a link nurse, but funding is an issue.

Swindon, Great Western Hospital

- Additional capacity being arranged by local consultant.
- Waiting times for new patients is stable. Any unused new patient appointments are converted to follow up appointments 2 weeks prior to the planned clinic.

Taunton, Musgrove Park Hospital

- Recruited to Cardiac Nurse link role post for a fixed period of 12 months.
- Agreed for additional PA in job plan for second consultant to support the paediatric cardiology services.
- WLI - Cardiac physiologist led echo clinics: 2/month started as interim measure to deal with waiting list.
- Clinical harm reviews being undertaken for long RTT.
- Continue to provide transition clinics twice a year and monthly cardiac MDT meetings to discuss complex cardiac cases - every 4th Wednesday.

Truro, Royal Cornwall Hospital

- Waiting for progress on Cardiac Nurse business case - case had been submitted for funding approval.
- Cardiac scientist has re-joined team 2 days a week after maternity leave. Working on how best to utilise her skills, with some standalone clinics and some clinics alongside

Risks / Concerns to be escalated

Exeter, Royal Devon and Exeter Hospital

- Attempts to secure modern, approved digital storage systems by using Medcon adopted by our adult colleagues within the RDE have not been financially supported. There is currently no mechanism to store images for > 3 months on our PACS system. Images up until July 31st 2021 are on DVDs.

Gloucester, Gloucestershire Hospital

- Substantial increase in waiting list post-Covid, with multifactorial lack of capacity.
- Need to change job plans to accommodate all visiting clinics, plus necessary admin.
- Need to develop a case for a 3rd PEC, plus consider succession planning.
- Have temporary secretary at present, awaiting appointment to the permanent post.
- Challenges with change of visiting Consultant and who their replacement will be - now known - thank you.

Torquay, Torbay District Hospital

- Current cardiac specialist leaving the network. No plans for specialist clinics at Torbay from January 2022

Truro, Royal Cornwall Hospital

- Continued issues with pending list for visiting consultant. Delays in organising additional clinics has resulted in no significant improvement.

Actions / Support required from network

Gloucester, Gloucestershire Hospital

- Ongoing support and understanding whilst we work through this difficult period. Emphasis to the Departmental leads of the shortcomings of the service, including lack of designated nursing support.

Torquay, Torbay District Hospital

- Support in maintaining and scanning current complex cases that would have been seen by visiting specialist

Level 3 Paeds – South Wales

Key Updates

Swansea Bay, Singleton Hospital

- New paediatric cardiology physiologist is progressing well following the retirement of senior physiologist, who will also be returning to work part time on a retire-and-return arrangement. Planned a meeting to consider expanding the role for the physiologist-led clinics

Risks / Concerns to be escalated

Swansea Bay, Singleton Hospital

- Waiting lists are currently high - this is partly because of increased demand (referrals from GPs have increased significantly since Covid-19 restrictions have been lifted) and partly because our 3 neonatal consultants who are providing a local cardiology service for children of all ages are only able to provide a limited number of outpatient clinics.
- Still have no general paediatricians with an interest in cardiology in our health board, despite trainees applying who have expertise.

Actions / Support required from network

Swansea Bay, Singleton Hospital

- Would value network support in making the case for paediatrician with a special interest in cardiology to be prioritised in future consultant appointments

Level 2 (Cardiff) Paeds- Dr Alan Pateman

Key Updates

- None noted

Risks / Concerns to be escalated

- Repatriation of patients from Bristol to Cardiff after procedure.
- Availability/ accuracy of discharge summaries from Bristol following intervention/ surgery.

Actions / Support required from network

- None noted

Level 1 (Bristol) Paeds – Steven Pike

Key Updates

- Elective programme continues, however challenging to maintain activity due to extreme operational pressures.
- Outpatients reduced capacity due to social distancing - currently booking 8 per clinic instead of 10-12. Having effect on waiting list size.
- Ongoing staffing shortages on junior doctor rota.

Risks / Concerns to be escalated

- Outpatient overdue follow up remains high and has increased by 290 since Q1.
- Wait to first appointment remains high although has reduced slightly.
- Outpatient capacity has been increased by 20% as part of job planning although this is unlikely to be sufficient to deal with backlog.
- Waiting list initiatives are encouraged as well as additional clinics when inpatient work is cancelled.

Actions / Support required from network

- None noted.

Item 8 – Patient Rep Update

December 2021



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Patient Rep update



Heart Heroes hubs, 'I can' pilot project & linking in with Youth @ Heart



Network newsletter – patient stories, role of patient rep.



Network website review project group in 2022



ACHD psychology webinar scoping exercise – sharing ideas and thoughts.



If a project involves patient care, a patient representative should be involved.

Equity of access

Seamless care

Meeting national standards

Continual improvement

Patient voice

15:20

Refreshment break

Board resumes at 15:35



South Wales and South West
**Congenital Heart
Disease Network**



15:35

Item 9: Research:

A feasibility pilot – a personalised physiotherapy-led remote ACHD cardiac rehabilitation programme

Caroline Evans

Clinical Specialist Cardiology Physiotherapist



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[https://forms.office.
com/r/FG2hv77cJK](https://forms.office.com/r/FG2hv77cJK)

December 2021

Background



- 85% CHD pts reach adulthood.
- Many ACHD pts sedentary, obese & increased CVS risk factors.
- Sedentary lifestyle - doubles risk of serious disease & premature death.
- Impaired exercise tolerance- Increase risk of procedures & length of stay.
- ACHD Consensus guidelines recommend exercise as Rx.
- ? What exercise & ? how.
- CHD patients should be encouraged to achieve UK PA activity guidelines ;

Be physically active every day , x2 strengthening/ week, accumulate 75minutes vigorous or 150 mins moderate activity per week & minimise sedentary time.

- Remote CR acquired pts; efficient, cost effective, improved uptake & adherence.
- CHD lifelong follow up's; potential substantial cost savings & benefits.

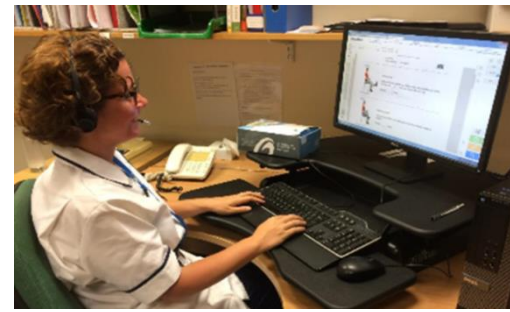
The Challenge?

- ♥ Unique Individuals
- ♥ A&P, devices, PMH, DH, Exercise tolerance & Psychology.
- ♥ Cardiac rehab commissioned for PCI, MI and Grafts.
- ♥ Age appropriate Cardiac Rehabilitation.
- ♥ Geography- expense.
- ♥ Accessible- employment/ college/ family.
- ♥ European consensus guidelines exercise counselling- every pt encounter for most CHD pts
 - ♥ Time constraints
 - ♥ PA advice during routine primary care doesn't = behavioural change

Objectives

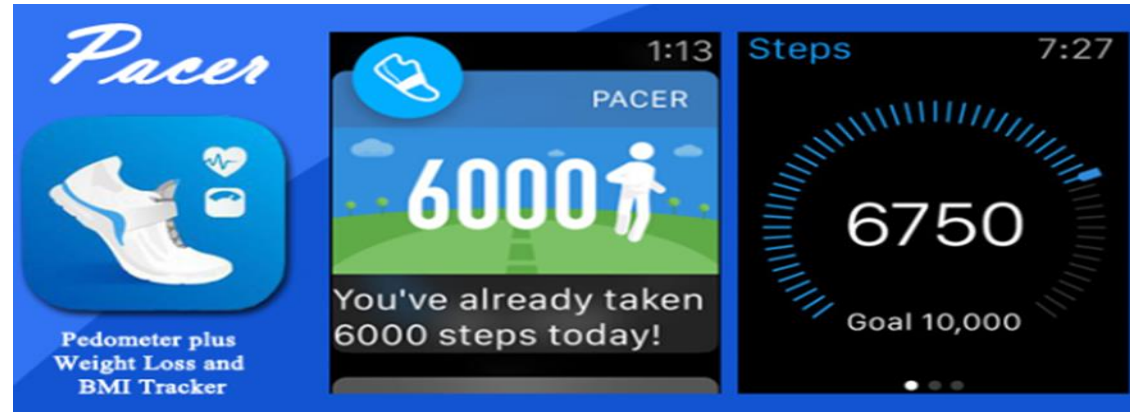
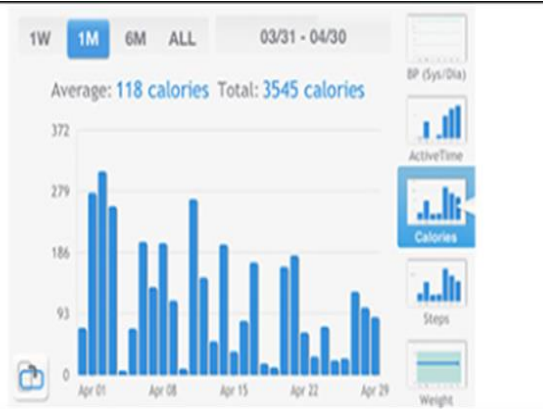
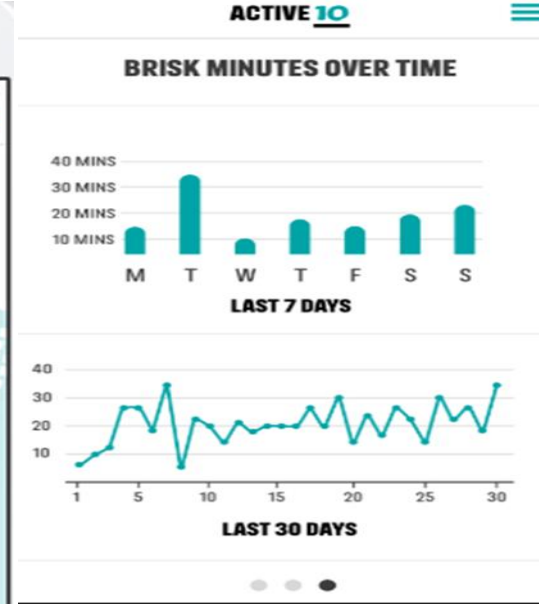
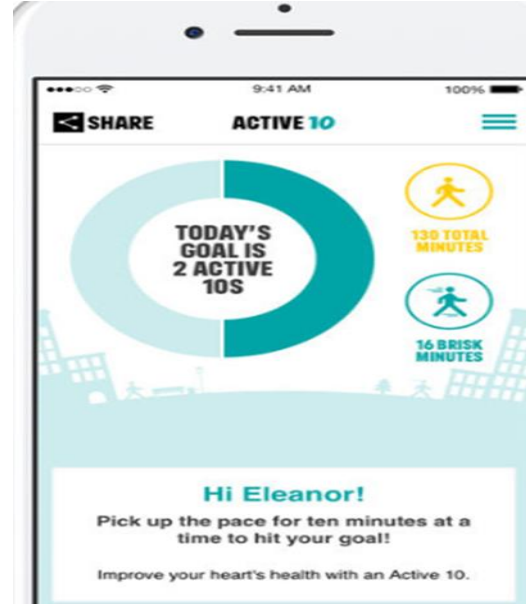
- 1. Determine the feasibility of physiotherapy led remote cardiac rehabilitation for ACHD pts and quantify the impact on physical activity levels and well-being.***
- 2. To discover if technology supported program would increase the activity levels of ACHD patients.***

Methodology



- ♥ Consultants referred sedentary complex ACHD pts from South west over 3/12.
- ♥ Inclusion criteria- ACHD, English speaking, consented to telephone consultations.
- ♥ Pregnant pts excluded.
- ♥ 12/52 supported individualised exercise programme, lifestyle advice & education.
- ♥ Single senior physiotherapist X5 consultations (1 hr initial, x4 20 minute follow ups).
- ♥ Holistic Assessment for exercise (face to face or remote).
- ♥ Coaching, Motivational Interviewing & goal setting via telephone consultations & apps.
- ♥ Decrease Physical & Psychological Barriers.
- ♥ Walking, Strengthening, Inspiratory Muscle Training & individualised program (preferences & goals).
- ♥ Support for exercise discharge options.

Apps



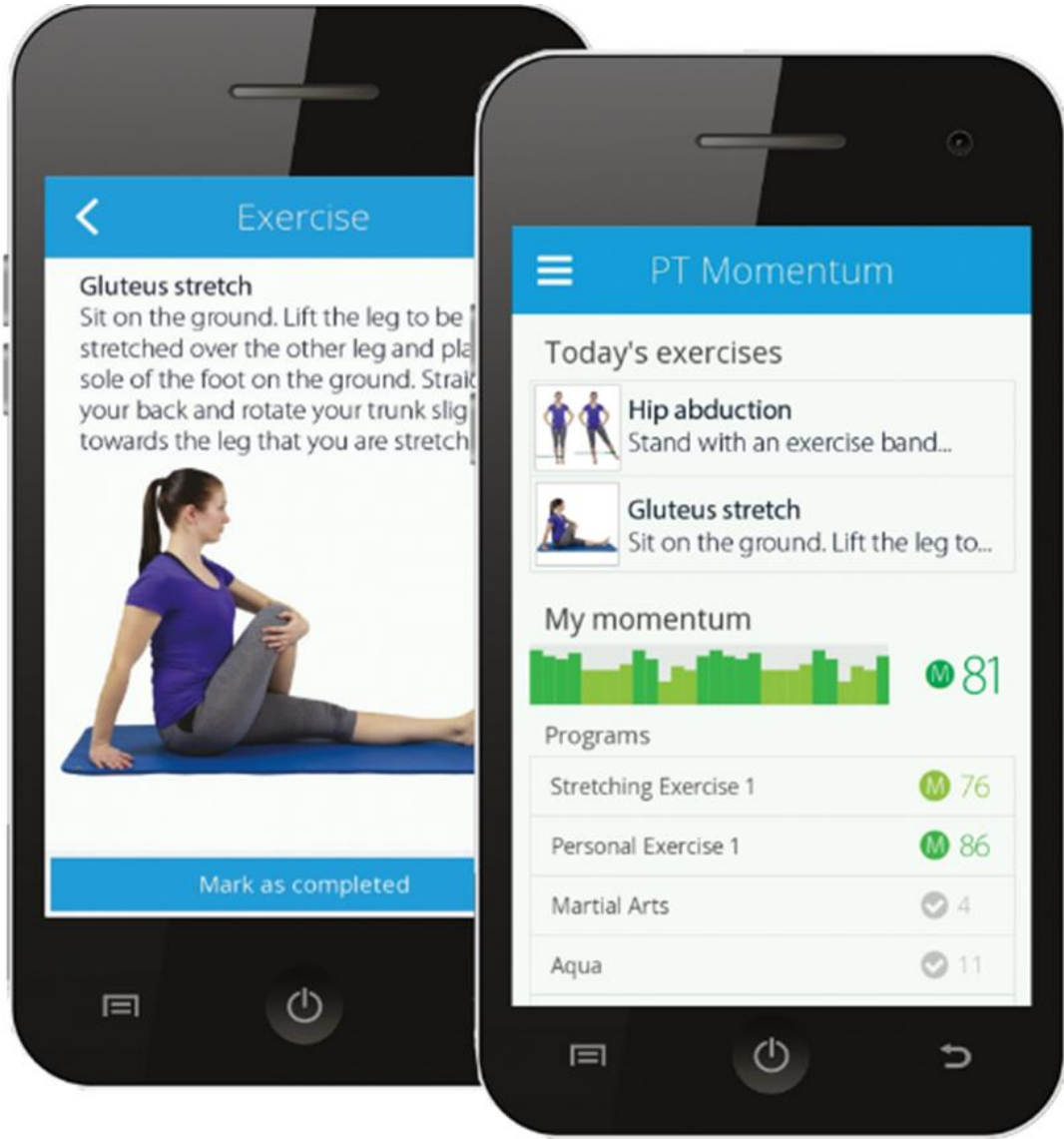
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Equity
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standards

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improvement

Patient
voice

Inspiratory Muscle training

- ♥ 44% ACHD pts lung abnormalities.
- ♥ IMT improves strength & endurance of diaphragm.
- ♥ 6/52 daily training Increase exercise tolerance, ventilatory efficiency & resting cardiac output in heart failure & Fontan's pts.
- ♥ Face to face patients only.
- ♥ 30 breaths x2 daily-40% Maximal inspiratory Pressure.
- ♥ Inspiratory load increased.



Outcome measures

- Physical Activity Self Efficacy Questionnaire.
- UK PA guidelines 2019.
- Short Form 12.
- Satisfaction With Life Questionnaire.
- Reported Barriers to exercise.

Results

Participants

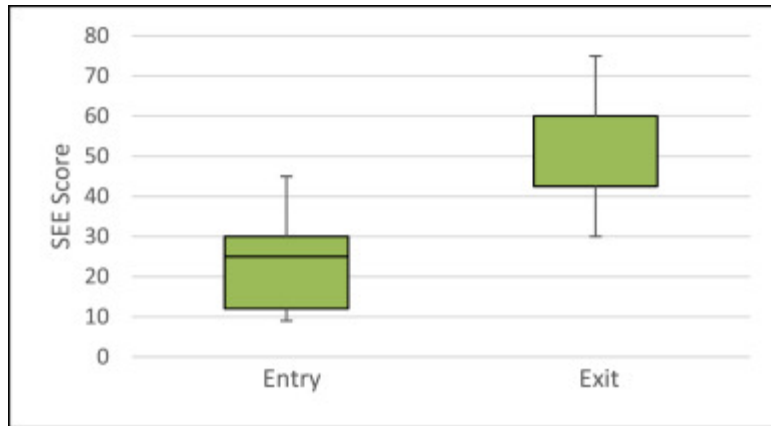
- 23 patients referred
- 11 completed program (3 with learning difficulties)
- Reasons for not completing; Failure to attend initial appointment (7), lack of interest (1), Too unwell (1), Death- unrelated to program (1), not contactable on last consultation (1)
- 10 had initial face to face- 9 telephone & 1 email consultations.
- 5 telephone consultations only.
- Cardiac diagnosis; Fontan circulation (6), Transposition great arteries with Senning repair (1), Complete heart block (1), Pulmonary stenosis (1), Atrial septal defect (1).
- Mainly females (9) age range 18-61 (median 24).

Results

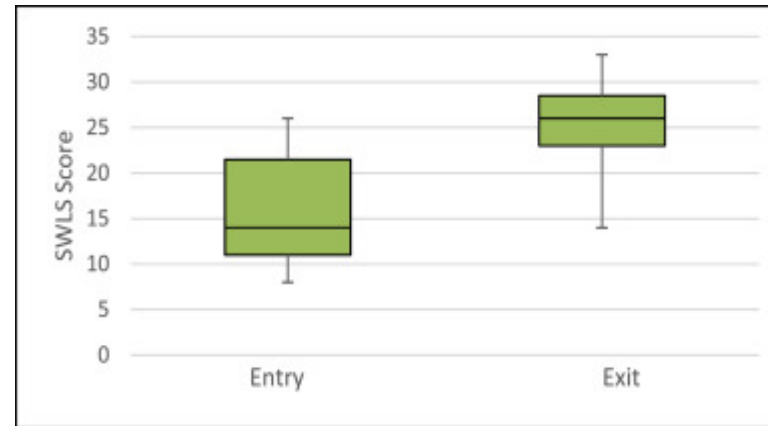
Well-being

Improvements seen in Self Efficacy Exercise mean increase of 23 (SD12) and a mean improvement of 10 (SD4) in Satisfaction With Life Scale.

Interquartile range for entry and exit SEE



Interquartile range for entry and exit SWLS



Barriers to exercise

| Barriers to exercise | Entry | Exit |
|------------------------|-------|------|
| Disability | 4 | 3 |
| Fear of exercise | 4 | 0 |
| Time constraints | 1 | 0 |
| Unmotivated | 1 | 0 |
| like to be more active | 1 | 6 |
| No barriers | 0 | 1 |

Onward referrals

- 3 to psychologist
- 3 to MSK physiotherapist

Ten participants completed their long-term goals

Apps

- 9 pts used the app.
- Reasons for not using device; lack of data storage (1) Lack of device (2).
- Most used selection
- 8 pts Active 10 & PT momentum.
- 2 used C25K, 3 Pacer.
- 3 used no apps.

IMT

- 5 pts prescribed IMT.
- 3 completed the program (1 inadequate technique, 1 focused on other exercises).
- 3 reported easy to use, less breathless and physically able to achieve more.

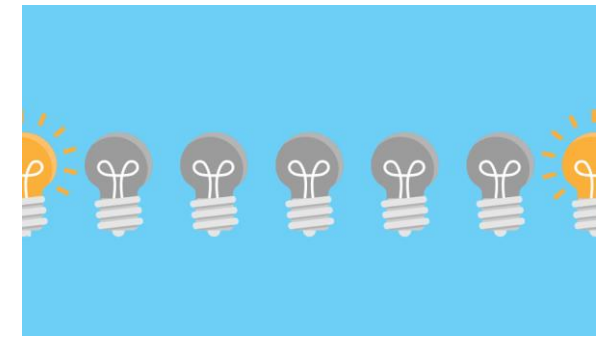
Amount of PA

Initially no patients achieving the UK PA guidelines.

Final **all** pts forefulling UK PA guidelines.

Both patients & referring clinicians found the remote cardiac rehabilitation service both beneficial and acceptable

Discussion



- Small numbers/ time constraints
- 11/23 48% achieved national PA guidelines translated to total ACHD population, significant clinical benefit.
- Pts with learning difficulties Increased SEE, SWLS and PA levels.
- Pilot- no control group
- Patients did not attend initial appointment ? education, ? readiness for change, ? fear of exercise.
- Quantitative data -CPET.

Conclusion

- Remote cardiac rehabilitation
- Feasible.
- Acceptable.
- Allows access to individualised, exercise advice & prescription.
- Improves activity levels and quality of life.

Further work to;

- Improve uptake.
- Extend to larger patient numbers.
- Long term adherence post remote cardiac rehabilitation.

What next?

- ♥ Secure long term funding
- ♥ Pre habilitation
- ♥ Attend anywhere consultations
- ♥ Supervised exercise sessions (face to face or remote)
- ♥ Individualised exercise prescription for all CHD



Thank you!

- Prof GA Stuart , Dr S Curtis , Dr R Bedair, Dr M Turner & Dr G Szanths.
- South Wales & South West Congenital Heart Disease Network.
- Above & Beyond GUCH Charity.



“I’m prescribing exercise. Think of it as a stress pill that takes 30 minutes to swallow.”

Reference

C. Evans, AG. Stuart, S. Curtis, R. Bedair, M. Turner, G. Szantho.

A feasibility pilot- a personalised physiotherapy led remote ACHD cardiac rehabilitation program.

International Journal of Cardiology Congenital Heart Disease volume 5, October 2021,100220

[A feasibility pilot- a personalised physiotherapy led remote ACHD cardiac rehabilitation program](#)

15:50



Item 10: Research update

Kelly Saunders, Gemma Dibble
On the behalf of Karen Sheehan

December 2021



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Item 10 - Network Board Update

- Quarter 2 update 2021/22
- Work plan 2021/22

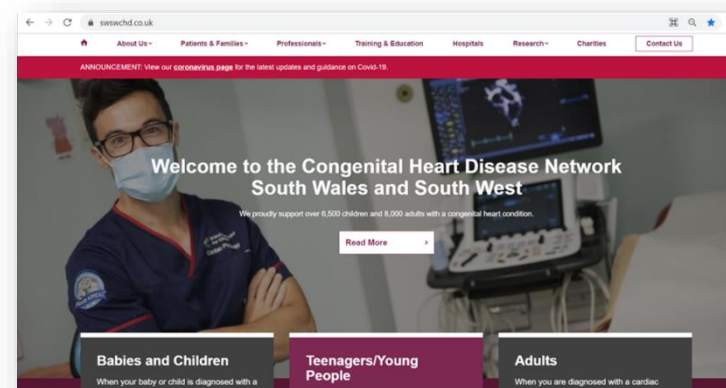
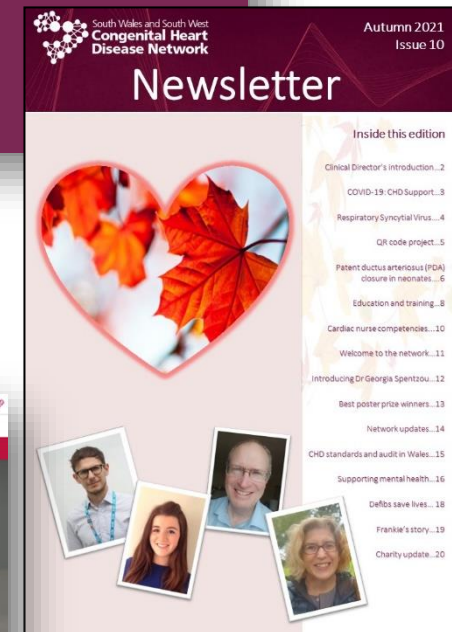
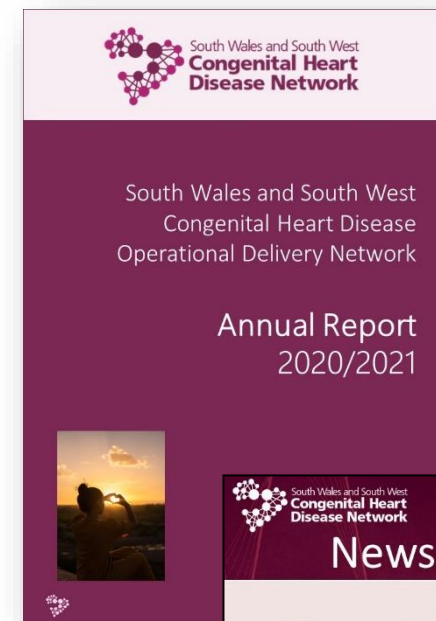


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Headlines: Sept 2021– to date

- ✓ Paediatric CHD Nurse 2021 webinar series completed (BRHC CNS team)
- ✓ Network Autumn 2021 Newsletter published
- ✓ Published annual report 2020/21
- ✓ ACHD study day with recordings published on network Future Platform.
- ✓ Third network cardiac physiologist meeting held (Daniel Meiring)
- ✓ Monthly Link Nurse level 3 drop in sessions
- ✓ L1& L2 Cardiac Nurse Study Day and networking event
- ✓ Presented at national CHD networks paediatric nurses education event for nurses across the UK (Jess Hughes, Shafi Mussa)
- ✓ PEC education forums (Dirk Wilson / Nigel Osborne)
- ✓ Psychology bite-size event 'providing cardiac psychology in all of our pathways' (Ness Garratt, Rachel Herrick and Vanessa Cook)
- ✓ Network M&M held in September 2021 with speakers from across the network
- ✓ ACHD workforce meetings (held July & September)
- ✓ Continued to lead National Networks of CHD networks bi-monthly conference calls
- ✓ Self-Assessment process in Wales is underway
- ✓ New website homepage – rotating images



Equity
of access

Seamless
care

Meeting
national
standards

Continual
improvement

Patient
voice

Item 10.2: Current Work plan 2021/22

| Status | No of items | Titles | Comment |
|-----------------------------------|-------------|--|--|
| Complete | 4 | <ul style="list-style-type: none"> •See workplan for details | Several self-contained pieces of work already completed for the year |
| Green - progressing on target | 27 | <ul style="list-style-type: none"> •See workplan for details | The majority of our work-plan is progressing and on target. |
| Amber - progressing behind target | 6 | <ul style="list-style-type: none"> •CHD Procedures guidance as per Specialised Services Circular 1888 •CHD Recovery •Fetal pathway between level 2 and level 1 •Image sharing •Nursing strategy •Psychology - high quality support for patients and families | Several work areas have partially progressed but have been delayed by external factors, e.g. COVID-19 |
| Red - not able to progress | 1 | <ul style="list-style-type: none"> •Paediatric disease related guidelines (Fontan's and Coarctation of Aorta) | Currently not able to progress specific work because of external factors. Discussed in Clinical Governance group |
| On hold | 7 | <ul style="list-style-type: none"> •5 year strategic plan •Advanced care in network •Governance structure •Lost to Follow-Up Patient engagement meetings •Pharmacy in the Network •Transition | Strategic decision to place this work on hold because of insufficient ODN core team capacity. To be reviewed now that additional capacity made available - in process of relaunching transition project. |

Work Plan 2022/23

- Need to review, prioritise and develop our work plan for 2022/23.
- Work plan is owned by the CHD Network Board and delivered by the core team and network members.

Deadlines

- Draft to NHSE by end January 2022
- Sign-off by SWSW CHD Network Board in March 2022

Network member input

- Priorities or detail?
- Email call for volunteers (Dec-Jan)

Item 11: National Updates – Dr Andy Tometzki

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Item 11: Regional Update South Wales – WHSSC – Andrea Richards/Kimberley Meringolo

Providing a verbal update

Key Updates

Risks / Concerns to be escalated

Actions / Support required from network

Item 11: Regional Update: South West – Specialised Commissioning - Claire Kennedy

Key Updates

- **System Working** – Starting to use CYP System Leads to engage with some network pieces of work – e.g. Long Term Ventilation in PCC ODN. This should pave the
- **Peripheral Clinic SLA** - Has been supported by Region. Now sitting with Bristol to progress.
- **PCC Surge Planning** – Plans approved regionally and nationally. Starting to see an increase in demand. SW and SE have moved in and out of OPEL 3 over the past few weeks. Likely to impact on electives as we progress through winter. Surge plans continue to be reviewed and updated to support escalation process.
- **Women’s & Children’s Programme Board** – last meeting 23rd Nov. Confirmation that Network workplans need to be submitted in January for review and sign off in Feb.
- **Risk Management** – Spec Comm risk register now being shared with Networks on the last day of each month. Training on risk SOP took place through Sept.
- **Governance Process for reviewing standards/models of care** – SiC and PCC have now adopted same strategy for self assessment as CHD. Self assessments have begun in CHD and will commence in SiC and PCC. Plan to share reviews through System Partnership Boards

Risks / Concerns to be escalated

- Alignment of regional waiting list analysis with the ODN efforts to collate waiting list data, to support targeted restoration.
- Lack of clarity around contracts and finance framework for the future.

Actions / Support required from network

- ODN intelligence of risks and issues in relation to restoration.

14:30

Item 12: Risk Register Report

Please refer to paper : 12 SWSW CHD Network Risk Report December 2021



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16:20 Item 13: Meeting Feedback

Please take a moment to complete this quick survey – your feedback is important to us and helps us plan for future events.

<https://forms.office.com/r/FG2hv77cJK>



To use the QR codes

1. Open your device's camera or download a free QR code reader
2. Point your camera at your chosen QR code
3. The link should open as a pop up!

Thank you!



16:25

Item 14: Any Other Business

Equity
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Thank you & future meetings for your diaries

Next CHD Network Board:

Wednesday 9th March 2022,

14:00 – 16:30

