



Report Title	Chair’s Report	Agenda Item	3.1		
Meeting Title	Joint Committee	Meeting Date	06/09/2022		
FOI Status	Public				
Author (Job title)	Chair of WHSSC				
Executive Lead (Job title)	Committee Secretary and Head of Corporate Services				
Purpose of the Report	The purpose of this report is to provide Joint Committee members with an update of the issues considered by the Chair since the last Joint Committee meeting.				
Specific Action Required	RATIFY <input type="checkbox"/>	APPROVE <input type="checkbox"/>	SUPPORT <input type="checkbox"/>	ASSURE <input type="checkbox"/>	INFORM <input checked="" type="checkbox"/>

Recommendation(s)

Members are asked to:

- **Note** the report.

CHAIR'S REPORT

1.0 SITUATION

The purpose of this report is to provide Joint Committee members with an update of the issues considered by the Chair since the last Joint Committee meeting.

2.0 BACKGROUND

At each Joint Committee (JC) meeting, the Chair presents a report on key issues that have arisen since its last meeting.

3.0 ASSESSMENT

3.1 Chair's Action – Interim Chair of the All Wales Individual Patient Funding Request (IPFR) Panel

A Chair's Action was taken on 27 July to appoint an interim Chair to the All Wales IPFR Panel for a 6 month period, and a letter was issued to Joint Committee members on 27 July 2022 confirming the action taken. The decision will be taken to the Joint Committee meeting on 6 September 2022 for ratification under the Chair's report. The letter is presented at **Appendix 1** for information.

WHSSC received two nominations via the NHS Wales Chairs Group and, following discussions with the two interested candidates, James Hehir, IM from Cwm Taf Morgannwg University Health Board (CTMUHB), agreed to undertake the role for a 6 month period on an unremunerated basis with effect from 27 July 2022.

3.2 Independent Member Recruitment Update

Further to the Independent Member (IM) vacancy that arose following Ian Phillips being appointed as the substantive Chair for the Welsh Renal Clinical Network (WRCN), and the Joint Committee agreeing that the CTMUHB audit lead IM role should be opened up to all HBs, I emailed the NHS Wales Chairs (4 August) and the Board Secretaries (10 August) to advise that WHSS were seeking to appoint two new WHSSC IMs. This is in accordance with the IM appointment process agreed by the Joint Committee on 18 January 2022. Eligibility is confined to HB IMs and expression of interest have been requested by 16 September 2022 and interviews will be held in October.

3.3 Integrated Governance Committee (IGC) 9 August 2022

I chaired the WHSSC Integrated Governance Committee (IGC) on 9 August 2022 and, among other items, the Committee considered the Corporate Risk and Assurance Framework (CRAF), the Q1 Integrated Commissioning Plan (ICP) update and the draft Annual Report 2021-2022.

3.4 Key Meetings

I have attended the following meetings, which in light of COVID-19, were all held via MS Teams:

- Regular catch up meetings with WHSSC IMs and WCRN Chair including objectives setting,
- Monthly meetings with WG to take forward Audit Wales' recommendation on IM Remuneration,
- Regular bi-monthly meetings with the Chair of the QPS Committee,
- WRCN Governance Review discussion session,
- All Wales IPFR Panel – discussions with 2 x IM candidates for the IPFR Chair position,
- Introductory meeting with new Interim Chair of IPFR Panel, James Hehir,
- WHSSC Quality & Patient Safety Committee on 9 August 2022; and
- NHS Wales Chairs Peer Group Meeting on 16 August 2022.

4.0 RECOMMENDATIONS

Members are asked to:

- **Note** the report.

Governance and Assurance	
Link to Strategic Objectives	
Link to Integrated Commissioning Plan	This report provides an update on key areas of work linked to Commissioning Plan deliverables.
Health and Care Standards	Governance, Leadership and Accountability
Principles of Prudent Healthcare	All
Institute for HealthCare Improvement Quadruple Aim	Not applicable
Organisational Implications	
Quality, Safety & Patient Experience	Ensuring the Joint Committee makes fully informed decisions is dependent upon the quality and accuracy of the information presented and considered by those making decisions. Informed decisions are more likely to impact favourably on the quality, safety and experience of patients and staff.
Finance/Resource Implications	There is no direct financial/resource impact from this report.
Population Health	The updates included in this report apply to all aspects of healthcare, affecting individual and population health.
Legal Implications (including equality & diversity, socio economic duty etc)	There are no specific legal implications relating to any of the issues outlined within this report.
Long Term Implications (incl WBFG Act 2015)	WHSSC is committed to considering the long-term impact of its decisions, to work better with people, communities and each other, and to prevent persistent problems such as poverty, health inequalities and climate change.
Report History (Meeting/Date/ Summary of Outcome)	-
Appendices	Appendix 1 - Chairs Action letter dated 27 July 2022.



GIG
CYMRU
NHS
WALES

Pwyllgor Gwasanaethau Iechyd
Arbenigol Cymru (PGIAC)
Welsh Health Specialised
Services Committee (WHSSC)

Your ref/eich cyf:
Our ref/ein cyf: KE.JE
Date/dyddiad: 27 July 2022
Tel/ffôn: 01443 443 443 ext. 8131
Email/ebost: Jacqueline.Evans8@wales.nhs.uk

WHSSC Joint Committee Members,

Dear Colleague,

Re: Interim Chair of the All Wales Individual Patient Funding Request (IPFR) Panel

I am writing to you to inform you that a Chair's action has been undertaken to appoint an interim Chair for the All Wales Individual Patient Funding Request (IPFR) Panel.

This action was taken in accordance with provisions of the WHSSC Standing Orders (SOs), specifically section 3.1.1 in relation to Chair's action on urgent matters whereby decisions which would normally be made by the Joint Committee need to be taken between scheduled meetings, and it is not practicable to call a meeting of the Joint Committee.

In accordance with the section 4 of the WHSSC SOs the Joint Committee has established a Joint Committee sub Committee structure that meets its own advisory and assurance needs and in doing so the needs of the constituent LHB's. The All Wales IPFR Panel is a sub committee of the Joint Committee and they ensure that the terms of reference for the IPFR Panel are formally approved by the Joint Committee.

On 10 May 2022 the Joint Committee were informed that Professor Vivienne Harpwood, Chair of the IPFR Panel, had stepped down from the role on the 1 April 2022 with immediate effect, due to competing pressures with her Health Board (HB) position, and that I had written to the NHS Wales Chairs Group to explain the challenge, and to request support in appointing an interim chair for a 6 month period from amongst their Independent Members (IMs) to ensure business continuity. In the interim, the Joint Committee agreed to appoint Dr Ruth Alcolado, Vice Chair of the IPFR Panel, as the Interim Chair of the IPFR Panel for a 3 month period.

I received two nominations via the NHS Wales Chairs group, and following discussion with the two interested candidates I am pleased to confirm that

Welsh Health Specialised Services Committee
Unit G1, The Willowford,
Treforest,
Pontypridd
CF37 5YL

Pwyllgor Gwasanaethau Iechyd Arbenigol Cymru
Uned G1, The Willowford,
Treforest,
Pontypridd
CF37 5YL

Chair/Cadeirydd: *Kate Eden*

Managing Director of Specialised and Tertiary Services Commissioning/Rheolwr Gyfarwyddwr Dros Dro Comisiynu Gwasanaethau Arbenigol a Thrydyddol: *Dr Sian Lewis*

James Hehir, IM from Cwm Taf Morgannwg University Health Board (CTMUHB) has agreed to undertake the role for a 6 month period, on an unremunerated basis with effect from 27 July 2022.

- The SOs state that:
"4.0.8 The membership of any such joint sub-Committees - including the designation of Chair; definition of member roles and powers and terms and conditions of appointment (including remuneration and reimbursement) - will usually be determined by the Joint Committee, subject to any specific requirements, regulations or directions agreed by the LHBs or the Welsh Ministers. Depending on the joint sub-Committee's defined role and remit; membership may be drawn from the Joint Committee, LHB Board or committee members, staff (subject to the conditions set in WHSSC Standing Order 4.0.9) or others."

Therefore, to ensure effective governance and in the interest of expediency to ensure business continuity for the IPFR Panel a Chair's action has been taken to appoint James Hehir, IM from CTMUHB as the interim Chair for the All Wales IPFR Panel for 6 months on an unremunerated basis.

In the interim WHSSC will continue discussions with Welsh Government (WG) on the complexities of the All Wales IPFR Policy process, specifically:

1. The authority of the Joint Committee to update and approve the terms of reference (ToR) of the Welsh Health Specialised Services Committee IPFR Panel,
2. The governance process for updating the All Wales IPFR policy; and
3. Consideration of a wider review of the both the policy and governance framework of IPFR panels in Wales.

Chair's Action

I confirm that by this letter, acting in conjunction with Dr Sian Lewis, Managing Director of WHSSC, and Professor Ceri Phillips, an IM of WHSSC, I have taken Chair's Action to make the interim chair appointment.

This matter will be reported on at the next Joint Committee meeting on the 6 September 2022 for ratification.

If you require further information or clarification regarding this matter, please contact Jacqui Evans, Committee Secretary, Jacqueline.Evans8@wales.nhs.uk in the first instance.

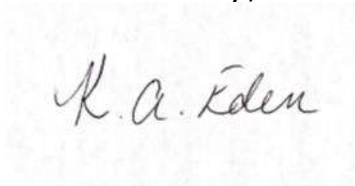
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Chair/Cadeirydd: *Kate Eden*

Managing Director of Specialised and Tertiary Services Commissioning/Rheolwr Gyfarwyddwr Dros Dro Comisiynu Gwasanaethau Arbenigol a Thrydyddol: *Dr Sian Lewis*

Yours sincerely,



Kate Eden
Chair

Cc – Dr Sian Lewis, Managing Director, WHSSC

Cc – Professor Iolo Doull, WHSSC Medical Director

Cc - Carole Bell, Director of Nursing

Cc – Dr Ruth Alcolado, Vice Chair All Wales IPFR Panel

**Welsh Health Specialised Services
Committee**

Unit G1, The Willowford,
Trefforest,
Pontypridd
CF37 5YL

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Chair/Cadeirydd: *Kate Eden*

**Managing Director of Specialised and Tertiary Services Commissioning/Rheolwr Gyfarwyddwr
Dros Dro Comisiynu Gwasanaethau Arbenigol a Thrydyddol:** *Dr Sian Lewis*



Report Title	Managing Director's Report			Agenda Item	3.2
Meeting Title	Joint Committee			Meeting Date	06/09/2022
FOI Status	Public				
Author (Job title)	Managing Director, Specialised And Tertiary Services Commissioning, NHS Wales				
Executive Lead (Job title)	Managing Director, Specialised And Tertiary Services Commissioning				
Purpose of the Report	The purpose of this report is to provide the Joint Committee with an update on key issues that have arisen since the last meeting.				
Specific Action Required	RATIFY <input type="checkbox"/>	APPROVE <input type="checkbox"/>	SUPPORT <input type="checkbox"/>	ASSURE <input checked="" type="checkbox"/>	INFORM <input checked="" type="checkbox"/>
Recommendation(s): Members are asked to: <ul style="list-style-type: none">• Note the report.					

MANAGING DIRECTOR'S REPORT

1.0 SITUATION

The purpose of this report is to provide the Joint Committee with an update on key issues that have arisen since the last meeting.

2.0 BACKGROUND

At each Joint Committee meeting, the Managing Director presents a report on key issues that have arisen since its last meeting. The purpose of the Managing Director's report is to keep the Joint Committee up to date with important matters related to WHSSC. A number of issues raised within this report may also feature in more detail within the Executive Directors' reports as part of the Joint Committee's business.

3.0 ASSESSMENT

3.1 Integrated Commissioning Plan (ICP) 2022-2025

On the 22 July 2022, the Director General/CEO NHS Wales wrote to WHSSC confirming that the Integrated Medium Term Plan, known by the Committee as the ICP, submitted on the 31 March 2022 was acceptable and had been noted by the Minister for Health and Social Services.

The Accountability Conditions were as follows:

1. Long term strategy
 - a) Development of your longer-term strategy to support the direction of the work programme.
2. Specialist services
 - a) Equity of access during recovery to cardiac, bariatric, paediatric, neuro and plastic surgery.
 - b) Support the transition to a single thoracic surgery unit for south Wales.

The letter is presented at **Appendix 1** for information. WHSSC have written to WG to clarify some elements of the letter.

3.2 Review of Secure Services - Single Commissioner for Mental Health Services

On the 3 August 2022, Welsh Government issued a letter to HB's to confirm that the recommendations of the Secure Mental Health Services had been accepted and to ensure that they were aware of recommendation 3.3.

Recommendation 3.3 states: *'Welsh Government, WHSSC and Health Boards*

should consider the benefits of a single national organisation commissioning integrated secure services’.

The letter suggested that the WHSSC Joint Committee should provide the mechanism for this recommendation to be considered and they have asked Dr Sian Lewis, Managing Director of WHSSC, to bring a paper outlining the options to a meeting of the Committee in the Autumn. Following that consideration, the expectation would be that the WHSSC Joint Committee will make a recommendation to be considered by Welsh Government.

A report outlining the options will therefore be presented to the Joint Committee (JC) in November 2022. It is anticipated that Committee Members will then need further time for this to be considered within individual HBs before a recommendation is made in January 2023 to Welsh Government. The WHSS Team will work closely with Management Group to develop the proposals to be presented to the JC. The letter is presented at **Appendix 2** for information.

3.3 Molecular Radiotherapy (MRT): the need for a Welsh strategy

On July 28 the Director General/Chief Executive NHS Wales wrote to advise that the Managing Director of WHSSC has been designated as the Senior Responsible Officer (SRO) for an All-Wales MRT Programme to produce a national strategy for MRT, and if the Programme deem it necessary, develop associated business case(s) to support the strategy. Welsh Government will provide WHSSC with up to £0.11m over the next 18 months to support the Programme. The letter is presented at **Appendix 3** for information.

3.4 Mental Health Specialised Services Strategy for Wales 2022-2028

Further to discussion at the JC meeting on 10 May 2022 and the update given on 12 July 2022 concerning the draft Mental Health Specialised Services Strategy 2022-2028 the draft strategy was issued bilingually via email to 368 stakeholders on 30 May 2022, accompanied by an easy read summary and a questionnaire for completion by 22 July 2022.

It was planned that feedback from the engagement process would be brought back to the September meeting of the Joint Committee (JC) and thereafter the document would be updated and circulated for a 12 week consultation and engagement process. Unfortunately due to workforce issues this has been delayed and the feedback will be presented to the November meeting of JC. It is envisaged that the final strategy will be brought to the JC in March 2023 for approval, prior to publication.

3.5 Value in Healthcare Bid – ATMP and Welsh Kidney Network (WKN) (previously known as Welsh Renal Clinical Network (WRCN))

WG wrote to NHS bodies in April 2022 inviting bids for additional funding for 2022-23 to support Value-Based Health and Care (VBHC). This funding is being targeted at high value interventions which can demonstrate improved

outcomes, to support the embedding of a VBHC approach at a system level across NHS Wales.

WHSSC submitted several bids and have received approval for An Advanced Therapy Medicinal Product (ATMP) and the Welsh Kidney Network (WKN) (previously known as Welsh Renal Clinical Network (WRCN)).

An ATMP is a medicinal therapy that is either a gene therapy, a cell therapy or a tissue-engineered product.

The project proposal involves the routine collection of outcome data for the CAR-T therapies in Wales, using existing infrastructure but with additional support from a Programme Manager, Data Manager and Clinical Consultant time. In addition, it involves the routine collection of PROMs data for patients undergoing CAR-T therapy. Welsh Government will provide total funding of up to £63,910 in 2022-23, and £115,819 on a recurrent basis for the delivery of the ATMP Outcomes Project.

The WKN submitted an ambitious bid to provide an all Wales Pre-habilitation Programme to support kidney patients to choose and commence the treatment that offers them the best outcomes. It is anticipated this will increase the number of patients who chose transplant or home dialysis as their first treatment choice which have been shown to be the most clinically and cost effective options. Welsh Government will provide a total funding of £444,460.

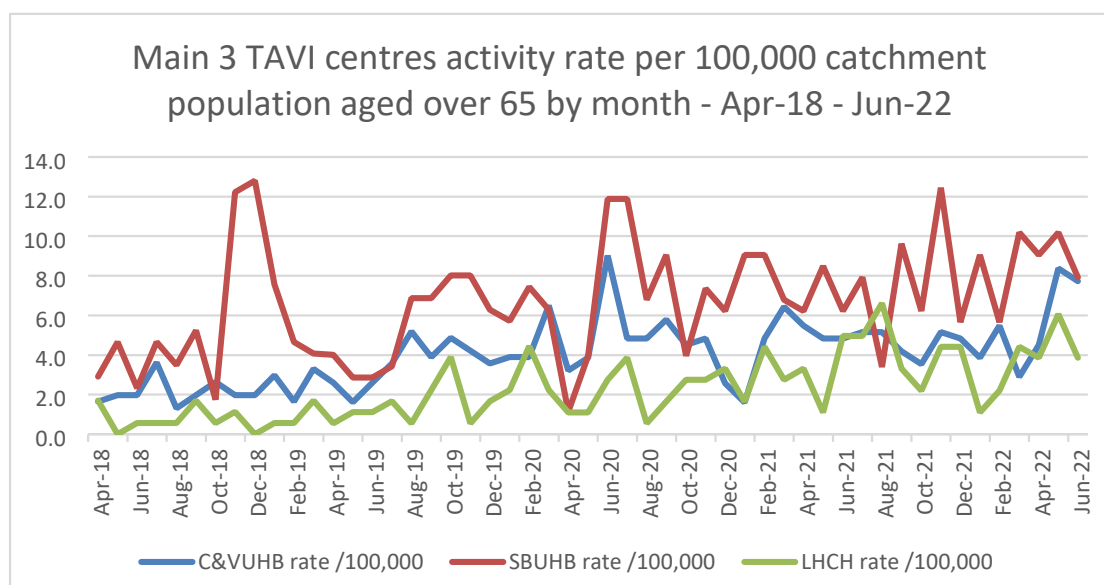
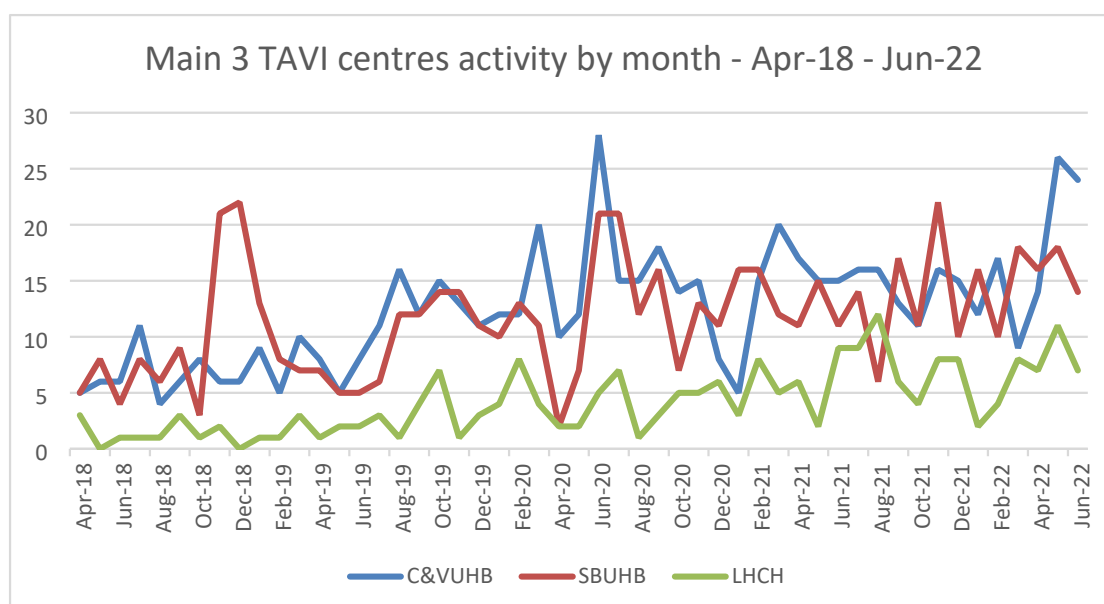
3.6 TAVI (Transcatheter aortic valve implantation)

TAVI activity has recently increased materially in the CVUHB and SBUHB cardiac centres. The initial feedback from the CVUHB services was that this was a clearance of a waiting list but it now appears that this trend will continue. There are a number of issues that need to be resolved regarding this latest trend and the WHSSC team will be working on this as an urgent piece of work.

The key issues include:

- Establishing a reliable outturn forecast from CVUHB and SBUHB for the financial year and projections for 2023/24 for the ICP if considered recurrent
- Establishing why the centres continue to use different devices at a materially different unit cost when outcomes generally appear to be no different
- Establishing whether the current TAVI policy is being adhered to and if not whether there is an urgent need to review and how non-compliance is dealt with. This will include exploring the comparative TAVI position in English centres and whether their practices are changing at a similar pace – to include understanding access rate variation between North and South Wales

- Revisiting the contracting framework to ensure there is appropriate incentive to use costs effective devices
- Establishing the recurrent impact of the change on overall surgical volumes including the need to re-align contracted volumes and recurrent disinvestment if surgical volumes are never to reach currently commissioned levels. This will include reviewing the impact of aging population together with the impact of any change in practice away from surgery.
- Reviewing the impact of total surgical demand on the sustainability of the current 2 centre cardiac surgery model



3.7 Appointment of Interim Director of Mental Health & Vulnerable Groups

I am delighted to report that we recently interviewed and selected David Roberts, previously Service Director for Mental Health (MH) & Learning Disabilities (LD) in SBUHB, take up a fixed term post as Director of Mental Health & Vulnerable Groups. David has worked within NHS Wales for many years and his skills and expertise make him ideally suited to lead on the implementation of the WHSSC Mental Health Strategy which is has just completed a period of stakeholder engagement.

4. RECOMMENDATIONS

Members are asked to:

- **Note** the report.

Governance and Assurance	
Link to Strategic Objectives	
Strategic Objective(s)	Governance and Assurance Choose an item. Choose an item.
Link to Integrated Commissioning Plan	This report provides an update on key areas of work linked to Commissioning Plan deliverables.
Health and Care Standards	Governance, Leadership and Accountability Choose an item. Choose an item.
Principles of Prudent Healthcare	Public & professionals are equal partners through co-production Care for those with the greatest health need first Only do what is needed Reduce inappropriate variation
NHS Delivery Framework Quadruple Aim	Choose an item. Choose an item. Choose an item. Choose an item.
Organisational Implications	
Quality, Safety & Patient Experience	The information summarised within this report reflect issues relating to quality of care, patient safety, and patient experience.
Finance/Resource Implications	There is no direct financial/resource impact from this report.
Population Health	The updates included in this report apply to all aspects of healthcare, affecting individual and population health.
Legal Implications (including equality & diversity, socio economic duty etc)	There are no specific legal implications relating within this report.
Long Term Implications (incl WCFG Act 2015)	WHSSC is committed to considering the long-term impact of its decisions, to work better with people, communities and each other, and to prevent persistent problems such as poverty, health inequalities and climate change.
Report History (Meeting/Date/ Summary of Outcome)	-
Appendices	Appendix 1 – Letter from Director General/CEO NHS Wales – WHSSC ICP Appendix 2 – Letter WG requesting views on the recommendations in the National Collaborative Commissioning Unit(NCCU) Secure Services Review

	Appendix 3 – Letter from the Director General/CEO NHS Wales Designation of SRO for an All-Wales Molecular Radiotherapy Programme
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Cyfarwyddwr Cyffredinol Iechyd a Gwasanaethau Cymdeithasol/
Prif Weithredwr GIG Cymru
Grŵp Iechyd a Gwasanaethau Cymdeithasol

Director General Health and Social Services/
NHS Wales Chief Executive
Health and Social Services Group



Llywodraeth Cymru
Welsh Government

Sian Lewis
Chief Executive
Welsh Health Specialist Services Committee

Our Ref: JP/BS/SB

22nd July 2022

Dear Sian

Integrated Medium-Term Plan 2022-2025

I am pleased to confirm that your Integrated Medium-Term Plan (IMTP) which you submitted on the 31 March 2022 is acceptable and has been noted by the Minister for Health and Social Services. This is in recognition of the development of integrated planning within WHSSC and demonstrates the position that the organisation is in as we move from the COVID pandemic towards recovery.

I expect the Committee to scrutinise the plan and that progress is monitored effectively over the forthcoming year, in particular against the Ministerial Priorities set out in the NHS Planning Framework, the Minister's delivery measures and the specific accountability conditions for WHSSC which are attached. Where necessary, any risks or challenges that need to be further addressed will need to be discussed and agreed at your Committee and communicated to Welsh Government via the routine governance arrangements (e.g. quarterly reporting against your IMTP). Where this necessitates any material changes to your IMTP in year will require you to advise me of these changes through an Accountable Officer letter.

There are a number of generic risks and challenges which all organisations are facing. These include the concerns about how COVID-19 will continue to impact on the NHS. This includes the need to balance the demands in the system between Urgent and Emergency Care and planned care and the way in which the system is able to respond to patients and their needs. Committee oversight of the role WHSSC can play in these is important and management of risk in these areas remains crucial.

I expect to see the Committee owning the plan which your organisation has submitted and for you and the senior team to lead on meeting the needs of your stakeholders and the commitments set out in the IMTP.

It was encouraging to see that a number of areas of good practice were highlighted by policy leads as part of the review process of the plans. These included the engagement work that had been done ahead of submission to ensure agreement with health board partners. There was a strong focus on restoring activity to pre-pandemic levels, which was recognised as being ambitious and yet realistic. Recognition of the quality statements for cancer was welcomed and the implementation of nationally optimised pathways.

However, there were a number of areas which the assessment highlighted as not covered sufficiently robustly in the IMTP. These include the need to develop the overarching clinical strategy for specialist services as this will strengthen your IMTP next time. The need to develop mental health services and specialist paediatric strategies.

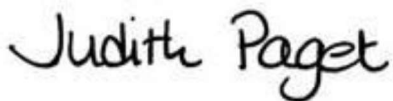
The WHSSC IMTP for 2022-2025 is therefore subject to a number of accountability conditions which I have set out in **Annex 1**. These are areas unique to your organisation and I expect to see demonstrable improvement over the next 12 months. The Minister is clear that the accountability conditions will also form part of the ongoing conversation that she will have with Chairs and delivery against these will be measures of success in their own right. The Accountability Conditions will form the basis of the ongoing engagement with the Welsh Government Planning team and policy leads.

As articulated in the Ministerial letter, the approval of the Integrated Medium-Term Plan does not equate to agreement to the detailed service changes, business case proposals or capital assumptions indicated within it. Nor does the plan approval confirm any validity in funding assumptions around additional revenue or capital funding other than that specified below. All service change and business case proposals will still be subject to:

- compliance with extant requirements set out in guidance or in legislation, and
- business cases and bids being subject to the normal business case approval process, including capital, and Invest to Save bid approval processes.

You have not requested financial flexibility as part of your IMTP, and none has been granted. I trust that this letter provides clarity on our expectations, but should you have any queries then please do not hesitate to contact me.

Yours sincerely



Judith Paget CBE

cc: Nick Wood, Deputy Chief Executive NHS Wales
Samia Edmonds, Planning Director
Jeremy Griffiths, Director of Operations
Andrew Sallows, Director of Recovery
Steve Elliott, Director of Finance, HSSG
Hywel Jones, Director of Finance FDU

WHSSC - Integrated Medium-Term Plan 2022-2025

Requirements and Accountability Conditions

The following requirements and accountability conditions should form the basis of planning and delivery discussion throughout the year as well as your internal monitoring and Committee assurance.

General requirements

- The '**Five Ways of Working**' and the Well-being of Future Generations Act should be central to WHSSC's approach. It is essential that your organisation continues to build on the progress made to utilise the five ways of working, sustainable development principles, to deliver your integrated plan. The organisation should ensure its well-being objectives are consistent with and continue to be supported by its planning arrangements.
- The **IMTP must be published** on your organisation's public facing website.
- **Reporting** must be submitted quarterly to provide an update on the plan. There should be reporting against the key milestones associated with that quarter, any slippage against the plan, next milestones and the mitigation of any new/emerging risks. Details of the reporting arrangements will be circulated in due course.
- The **Minimum Data Set (MDS)** must be refreshed on a quarterly basis.

Accountability Conditions

1. Long term strategy

- a) Development of your longer-term strategy to support the direction of your work programme.

2. Specialist services

- a) Equity of access during recovery to cardiac, bariatric, paediatric, neuro and plastic surgery.
- b) Support the transition to a single thoracic surgery unit for south Wales.



To: Health Board Chief Executives.

Cc: Dr Sian Lewis, Managing Director, WHSSC
Matt Downton and Sally Thompson, Welsh Government.

Eich Cyf/Your Ref:
Ein Cyf/Our Ref:

3 August 2022

Dear Colleague

The Welsh Government commissioned the National Collaborative Commissioning Unit to undertake a review of secure services in 2021 and the final report was submitted to the Welsh Government in March 2022 (attached at Annex A). The review was commissioned to achieve a greater understanding of the issues relating to secure mental health hospital care and made several recommendations to providers, commissioners, the Welsh Government and health boards.

The review informed a number of proposals that have been included in the Welsh Health Specialised Services Mental Health Strategy that has recently been out for a period of stakeholder feedback and on which there will be formal engagement later in 2022. The NCCU secure services review recommendations have also informed the allocation of the 2022-23 Mental Health Service Improvement Funding.

Amongst the recommendations to be considered nationally the secure services review highlighted the current fragmented approach to commissioning, with NHS Wales low secure hospitals managed by individual health boards (HBs) as opposed to being part of an integrated pathway with medium and high secure hospitals. This also applies to commissioning placements external to NHS Wales, which is split national and locally dependent on the level of security.

As the recommendations of the secure services review have been accepted by Welsh Government, the purpose of this letter is to ensure that all health boards are aware of recommendation 3.3 in the Review and to specifically request that your organisations agree a preferred commissioning model for all secure services. For ease of reference, recommendation 3.3 states: *'Welsh Government, WHSSC and Health Boards should*

Rydym yn croesawu derbyn gohebiaeth yn Gymraeg. Byddwn yn ateb gohebiaeth a dderbynnir yn Gymraeg yn Gymraeg ac ni fydd gohebu yn Gymraeg yn arwain at oedi.

We welcome receiving correspondence in Welsh. Any correspondence received in Welsh will be answered in Welsh and corresponding in Welsh will not lead to a delay in responding.

consider the benefits of a single national organisation commissioning integrated secure services'

It is suggested that the WHSSC Joint Committee should provide the mechanism for this recommendation to be considered and we have asked Dr Sian Lewis Managing Director of WHSSC to bring a paper outlining the options to a meeting of the Committee in the Autumn. Following that consideration, the expectation would be that the WHSSC Joint Committee will make a recommendation to be considered by Welsh Government.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Tracey Breheny', with a stylized, cursive script.

Tracey Breheny
Deputy Director of Mental Health, Substance Misuse and Vulnerable Groups

Cyfarwyddwr Cyffredinol Iechyd a Gwasanaethau Cymdeithasol/
Prif Weithredwr GIG Cymru
Grŵp Iechyd a Gwasanaethau Cymdeithasol

Director General Health and Social Services/
NHS Wales Chief Executive
Health and Social Services Group



Llywodraeth Cymru
Welsh Government

Dr Sian Lewis
Managing Director
Welsh Health Specialised Services Committee
By e-mail

Our Ref: MA/EM/2339/22

28 July 2022

Dear Sian

Molecular Radiotherapy (MRT): the need for a Welsh strategy

I am writing to thank you for the work WHSSC has done with the All Wales Molecular Radiotherapy (AWMOL) group to date towards a national MRT strategy to provide a sustainable and equitable service for our patients in Wales.

I wish to take this opportunity to confirm your appointment as SRO for an All-Wales Molecular Radiotherapy Programme (the Programme) to provide independent assurance, ensure good governance, and lead delivery of the Programme. Your accountability as SRO for the Programme is effective immediate.

In this role you will be accountable to the Deputy Director of Health Science at Welsh Government as Programme Sponsor.

As SRO you will chair a Strategic Programme Board with the specific goal to produce a national strategy for MRT, and if the Programme deem it necessary, develop associated business case(s) to support the strategy. I also anticipate that the Programme will remain closely linked to AWMOL to ensure they continue to provide their expertise to this work.

I can confirm Welsh Government will provide WHSSC with up to £0.11m over the next 18 months to support the Programme. This will be to fulfil the requests outlined within your submitted SBAR document around the resources required to deliver against this ambition.

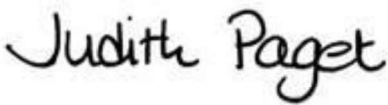
It is anticipated that upon completion of the strategic development work there will be a need for WHSSC, AWMOL and Welsh Government to collectively consider next steps required for the implementation phase.

In parallel to the Programme, I would also request that WHSSC conducts a formal review of national commissioning arrangements for MRT, inclusive of future therapies yet to be approved for use, such as Lu-177 PSMA. Please agree timescale for completing the review with the Deputy Director of Health Science.

Pending to the findings of the commissioning review, I also endorse in principle a decision by WHSSC to use AWMOL as a formal advisory body against national commissioning decisions for MRT.

The Health Science division at Welsh Government will continue to engage with you on these matters.

Yours sincerely

A handwritten signature in black ink that reads "Judith Paget". The script is cursive and fluid, with the first letters of each name being capitalized and prominent.

Judith Paget CBE



Report Title	Neonatal Transport – Update from the Delivery Assurance Group (DAG)		Agenda Item	3.3	
Meeting Title	Joint Committee		Meeting Date	06/09/2022	
FOI Status	Open				
Author (Job title)	Senior Project Manager				
Executive Lead (Job title)	Director of Planning				
Purpose of the Report	The purpose of this report is to provide an update from the Neonatal Transport DAG.				
Specific Action Required	RATIFY <input type="checkbox"/>	APPROVE <input type="checkbox"/>	SUPPORT <input type="checkbox"/>	ASSURE <input checked="" type="checkbox"/>	INFORM <input checked="" type="checkbox"/>
Recommendation(s): Members are asked to: <ul style="list-style-type: none">• Note the information in the report,• Note the update on the progress of the implementation of the Neonatal Transport Operational Delivery Network (ODN); and• Receive assurance that the Neonatal Transport service delivery and outcomes is being scrutinised by the Delivery Assurance Group (DAG).					

NEONATAL TRANSPORT – UPDATE FROM DELIVERY ASSURANCE GROUP (DAG)

1.0 SITUATION

The purpose of this report is to provide an update from the Neonatal Transport Delivery Assurance Group (DAG).

2.0 BACKGROUND

The DAG was established in January 2022, is chaired by the WHSSC Director of Planning and comprises of representation from all commissioning Health Boards (HB's) covered by the transport service and the three provider HB's at a clinical and managerial level.

The purpose of the group is to provide commissioner assurance on the performance of the service and to address any concerns from commissioners. The group meet bi-monthly and report directly to the Joint Committee (JC).

Due to availability of key HB staff, the July DAG was stood down but the Neonatal transport providers were asked to provide an up to date to WHSSC and JC for assurance.

3.0 ASSESSMENT

3.1 Report Highlights

The WHSS team have been working closely with the neonatal transport providers to develop an enhanced reporting tool for presentation to the JC to provide further assurance on the delivery of the service. A new report has subsequently been submitted to the DAG. This report provides data against a number of additional Key Performance Indicators, sets out the activity undertaken and provides actions taken and outcomes against any reported Datix incidents.

During May and June it is noted that 78 babies were transferred with 4 air transfers being jointly facilitated with EMRTS. Over 50% of the transfers were for capacity issues or repatriation rather than uplift of a sick baby. Capacity transfers should only be undertaken when there is no ITU capacity in the Network. However, the demand for capacity transfers is reflected in the current cot availability and staffing pressures and CHANTS have attempted to support units to maintain a safe service. Going forward, to ensure equity of service, a review of the night transfer criteria is required before the permanent 24hr model is in place.

Twelve transfers took place during the 8pm to 8 am out of hour's period. The transport sub-group have reviewed all night time transfers and consider them to be appropriate.

The CHANTS team undertook 100% of all referrals made within the time period. There were no Non-CHANTS transfers which is in line with 2021.

There were 4 datix reports (3 by Health Boards and 1 by the CHANTS team) submitted with the reporting period. All have been reviewed, actioned and closed with a process in place for shared learning.

The CHANTS team have implemented a parent feedback survey via a QR code but to date have not received any responses; this is a national issue and the Chair of the National Transport Group is taking this forward with parent groups. In the meantime at a local level the team have been driving forward some initiatives to try and improve parent feedback, this includes circulating a poster to all lead nurses for display in parent area and a request to share the QR code on parent group social media and on the Wales Maternity and Neonatal Network social media page.

Due to the enhanced data reporting and the small number of transfers undertaken there is a risk of being able to identify individual cases. Therefore the full report will be presented to the Joint Committee in committee meeting only.

3.2 Update on the Implementation of the Operational Delivery Network (ODN)

A business case was presented to the WHSSC Management Group (MG) in July to seek approval for the release of funding for the staffing structure for the ODN. The revenue costs requested for the ODN were £179k, which was £72k less than presented to WHSSC in the SBUHB initial case and within the funding allocated in the ICP. However members raised concerns regarding value for money in regards to the staffing model particularly noting that the costs were disproportional when considered against the benchmarking of other ODN staffing and equated to a management fee of £500 per transfer. Therefore the funding release was not supported and the MG asked the ODN Network Board to reconsider the options and to bring back to a future meeting for consideration. The WHSS team will work with SBUHB colleagues to consider the options with the aim of bringing an amended request to the MG in September 2022.

4.0 RECOMMENDATIONS

Members are asked to:

- **Note** the report,
- **Note** the update on the progress of the implementation of the Neonatal Transport Operational Delivery Network (ODN); and
- **Receive assurance** that the Neonatal Transport service delivery and outcomes is being scrutinised by the Delivery Assurance Group (DAG).

Governance and Assurance	
Link to Strategic Objectives	
Strategic Objective(s)	Governance and Assurance Choose an item. Choose an item.
Link to Integrated Commissioning Plan	Neonatal Transport service and the establishment of the DAG were included in the ICP
Health and Care Standards	Individual Care Safe Care Timely Care
Principles of Prudent Healthcare	Reduce inappropriate variation Choose an item. Choose an item.
NHS Delivery Framework Quadruple Aim	People in Wales have improved health and well-being with better prevention and self-management People in Wales have better quality and accessible health and social care services, enabled by digital and supported by engagement Choose an item. Choose an item.
Organisational Implications	
Quality, Safety & Patient Experience	The DAG is providing scrutiny on the service.
Finance/Resource Implications	The financial implications of the ODN are still being established.
Population Health	The updates included in this report apply to all aspects of healthcare, affecting individual and population health.
Legal Implications (including equality & diversity, socio economic duty etc.)	There are no specific legal implications relating to any of the issues outlined within this report.
Long Term Implications (incl WBFG Act 2015)	None identified
Report History (Meeting/Date/ Summary of Outcome)	-
Appendices	-



Report Title	Specialised Services Paediatric Strategy – Post Stakeholder Feedback			Agenda Item	3.4
Meeting Title	Joint Committee			Meeting Date	06/09/2022
FOI Status	Public				
Author (Job title)	Specialised Planning Manager – Women and Children				
Executive Lead (Job title)	Director of Planning				
Purpose of the Report	The Specialised Paediatric Services Strategy was recently issued for stakeholder feedback over a period of 4 weeks. This paper is requesting the comments received are noted and the WHSSC responses and amended strategy are supported for final publication.				
Specific Action Required	RATIFY <input type="checkbox"/>	APPROVE <input checked="" type="checkbox"/>	SUPPORT <input checked="" type="checkbox"/>	ASSURE <input type="checkbox"/>	INFORM <input checked="" type="checkbox"/>
Recommendation(s): <ul style="list-style-type: none">• Note the content of the paper,• Approve the proposed final version of the strategy; and• Support the proposed next steps.					

SPECIALISED PAEDIATRIC SERVICES STRATEGY POST STAKEHOLDER FEEDBACK

1.0 SITUATION

The Specialised Paediatric Services Strategy was recently issued for stakeholder feedback. This paper is requesting the comments received are noted and the WHSSC responses and amended strategy are supported for final publication.

2.0 BACKGROUND

A strategic priority set within the WHSSC 2021/22 was to develop a Paediatric Service Strategy. This work has been undertaken through a full programme structure, with a number of sub-groups that all had invited representation from all of the 7 Health Boards in Wales, overseen by a Programme Board.

The draft strategy was supported in July 2022 by Joint Committee and an exercise to seek a broader group of stakeholder views was undertaken. A letter was issued by the Managing Director of WHSSC seeking feedback on the strategic vision set out in the document, to further strengthen the WHSSC understanding of what is needed to commission services of the very highest quality for the population in Wales. The letter along with a pro-forma to collate the feedback was issued on the 1st of August 2022 with the closing date of 23rd of August 2022.

3.0 ASSESSMENT

16 separate pro-forma were returned from across NHS Wales, with a total of 141 individual comments. All comments and responses from the Women and Children Commissioning Team are included in Appendix 1. The proposed final version of the strategy with tracked changes is included in Appendix 2.

3.1 Next steps

Once approved the strategy will move to the implementation phase. A full Implementation Board will be established with representation from all 7 Health Boards in Wales. The Implementation Board will develop a detailed plan and timetable, it is proposed that bi-annual updates are provided to Joint Committee on progress.

4.0 RECOMMENDATIONS

Members are asked to:

- **Note** the content of the paper; and
- **Approve** the proposed final version of the strategy; and
- **Support** the proposed next steps

Governance and Assurance	
Link to Strategic Objectives	
Strategic Objective(s)	Implementation of the Plan Choose an item. Choose an item.
Link to Integrated Commissioning Plan	The development of a Paediatric Strategy is a strategic priority set within the WHSSC 2021/22 ICP.
Health and Care Standards	Effective Care Timely Care Staff and Resourcing
Principles of Prudent Healthcare	Reduce inappropriate variation Public & professionals are equal partners through co-production Care for Those with the greatest health need first
NHS Delivery Framework Quadruple Aim	People in Wales have improved health and well-being with better prevention and self-management People in Wales have better quality and accessible health and social care services, enabled by digital and supported by engagement The health and social care workforce is motivated and sustainable Choose an item.
Organisational Implications	
Quality, Safety & Patient Experience	
Finance/Resource Implications	The resource allocation for the implementation of the strategy is included at page 69 of the strategy
Population Health	N/A
Legal Implications (including equality & diversity, socio economic duty etc)	N/A
Long Term Implications (incl WBFG Act 2015)	The strategy is underpinned by the WBFG and is referenced throughout.
Report History (Meeting/Date/ Summary of Outcome)	12 July Joint Committee - supported
Appendices	Appendix 1 – Stakeholder comments and WHSSC responses Appendix 2 – Proposed final Specialised Services Paediatric Strategy

Specialised Paediatric Services 5 year Commissioning Strategy

Stakeholder Feedback

Comment number	Name of stakeholder organisation / individual	Page No.	Line Number	Section	Comments	WHSSC response
1	Powys Teaching Health Board	6			The strategy should focus on improving the outcomes and experience for children and young people with specialised health needs in all health boards in Wales.	Thank you for your comment. The remit of the Quality and Governance sub-group was to consider how outcomes and experiences could be measured during implementation of the strategy and beyond, as it is recognised that they are central to the commissioning of paediatric services. The recommendation of the sub-group, which was accepted by the Programme Board was to request all services to report in line with the NHS Wales Quality and Safety Framework (Welsh Government 2021), using the Institute of Medicine (1999) six domains of quality to support a systematic approach, STEEP. This will ensure that there are robust metrics for measuring experience and outcomes that are rooted within all commissioned services, appreciating that the metric will be specialty specific and therefore will need be phased over the 5 year implementation period.
2	Powys Teaching Health Board	6			A value-based health care approach means improving outcomes, experience and cost. There needs to be a greater emphasis on shared decision making with children and families. There is little information about comparative clinical outcomes and costs for children and young people across health boards within the draft strategy.	Thank you for your comment. The remit of the Quality and Governance sub-group was to consider how outcomes and experiences could be measured during implementation of the strategy and beyond, as it is recognised that they are central to the commissioning of paediatric services. The recommendation of the sub-group, which was accepted by the Programme Board was to request all services to report in line with the NHS Wales Quality and Safety Framework (Welsh Government 2021), using the Institute of Medicine (1999) six domains of quality to support a systematic approach, STEEP. This will ensure that there are robust metrics for measuring experience and outcomes that are rooted within all commissioned services, appreciating that the metric will be specialty specific and therefore will need be phased over the 5 year implementation period.
3	Powys Teaching Health Board	7			The wording of strategic objective three needs to be clearer.	Thank you for your comments. Amendments have been made to the wording to provide clarity.
4	Powys Teaching Health Board	8			It needs to be clear how the views and experiences of children and young people with specialised health care needs are helping to shape strategy development.	The development of the Paediatric Strategy took place during the COVID-19 pandemic which by nature made engagement with children and families a challenge. We recognise this and have scheduled a meeting with the Children's Commissioner for Wales to explore how best to engage throughout the implementation phase.
5	Powys Teaching Health Board	12			This section needs to reference any significant issues for the specialised services provided in England for the children of Welsh Health Boards, for example the commissioning arrangements for specialised services in England have changed with the introduction of Integrated Care Systems.	Thank you for your comment, we are not proposing through the implementation of the strategy to change the commissioning arrangements for the population of Wales. We continuously engage with both providers and NHSE Specialised Commissioning to ensure no national policy impacts on the Welsh population.
6	Powys Teaching Health Board	19			The narrative explanation in Figures 5 and 6 needs to be clearer. As we are in 2022 – and this strategy is for the next 5 years - the key issue is the plateauing and falling child population and the sustainability issues which arise from this.	Thank you for your comment, we recognise the projected reduction and will continuously monitor service sustainability through the life span of the 5 year strategy.
7	Powys Teaching Health Board	22			WHSSC only commissions the specialised element of paediatric neurology.	Thank you for your comment, this applies to a number of paediatric services. For the purposes of the flow charts it includes the commissioned elements of the service as per the activity returns. We have amended the language in paragraph 2.3 to further clarify.
8	Powys Teaching Health Board	24			Figure 2.3.3 the narrative needs to include the flow to Birmingham Children's Hospital.	Thank you for your comments the illustrations in section 2.3 use information that WHSSC receives on commissioned activity and uses financial year 2019/20 information (pre-Covid-19). In some instances, links may be missing and this is mainly due to insufficient information from providers.
9	Powys Teaching Health Board	25			Figure 2.3.4 the narrative needs to state that the flow for Powys patients is variable dependent on geographical location.	Thank you for your comment. The narrative has been amended as per your suggestion.
10	Powys Teaching Health Board	29			Figure 2.3.10 Birmingham Children's Hospital is going to need to remain a provider for some children in Powys due to geography.	Thank you for your comment, we are not proposing any changes to the flow of Powys resident and the illustrations in section 2.3 use information that WHSSC receives on commissioned activity and uses financial year 2019/20 information (pre-Covid-19). In some instances, links may be missing and this is mainly due to insufficient information from providers.
11	Powys Teaching Health Board	36-38.			It would be helpful if the table showed the proportion of the additional investment which has gone to each provider.	Thank you for your comment, for the purposes of the strategy we do not feel that it is appropriate to publish however we are happy to provide detail of your HB contribution separately.
12	Powys Teaching Health Board	39-42.			Generally, the more alignment there is between England and Wales in terms of what is regarded as a specialised service the better - due to cross-border flows and to enable better benchmarking of outcomes and efficiency.	Thank you for your comment, this was a key consideration of the collective commissioning group and recommendations for amendments to the WHSSC list of commissioned services was supported by the Programme Board.
13	Powys Teaching Health Board	43			WHSSC should be commissioning services to achieve improved outcomes – not posts.	Thank you for your comment.
14	Powys Teaching Health Board	59			Theme 7 – there needs to be a greater focus on the skills needed not particular professional groups; there also needs to be reference to the new techniques likely to be implemented over the next 5 years.	Thank you for your comment, it is not an exhaustive list and the list is referenced as an example.
15	Powys Teaching Health Board	60-61.			The proposal in relation to an all-Wales "Co-ordinated structure to support the delivery of children's services" is not clear – including the relationship to the bodies and Committees with statutory accountabilities. The costs and benefits also need to be clear.	Thank you for your comment. It is recognised that such a structure is beyond the remit of WHSSC and therefore the strategy.
16	Powys Teaching Health Board	68			More detail is needed in relation to the financial analysis before the strategy is finally approved.	Thank you for your comments. A recurrent funding allocation has been approved within the WHSSC 2022/25 ICP. The utilisation of this funding will be subject to usual WHSSC scrutiny and processes including Management Group and Joint Committee.
17	Powys Teaching Health Board	68			There needs to be greater accuracy about the statutory bodies/Committees which have the powers to "approve."	The implementation of the strategy will be subject to usual WHSSC scrutiny and processes including Management Group and Joint Committee.
18	Powys Teaching Health Board				Transition: Legally a child is a person below their 18 th birthday. Some paediatric services may only accept new patients up to the 16 th birthday. There needs to be greater clarity about the arrangements and approach for children and young people aged 16-18 years old in terms of specialised services.	From a WHSSC commissioning perspective, transition is ordinarily at the age of 16 years, a position that was supported by Joint Committee (July 2022) for the commissioning and funding of high cost drugs. The WG transition and handover guidance defines children's health services as - The service providing healthcare to the infant, child and young person, including all providers in the primary, secondary, tertiary and community care setting. Children's health services generally care for children up to the 16th birthday. We appreciate that there are clinical and patient considerations to be made.
21	Cardiff and Vale UHB	41			Agree in full, with need to specify service and pathway into tertiary chronic pain service. Such a service is likely to have huge impact on local services in terms of paediatric physiotherapy demand. Concern that by having a 'tertiary chronic pain' service this is not 'providing therapeutic care closer to home' as per section 4.2 (page 52).	Thank you for your comment, the design and delivery of the specialised elements of the new service will be considered through the implementation phase. We recognise the barriers of commissioning only the specialised elements of the service as considered in the chapter 7, constraints.
22	Cardiff and Vale UHB	22			Lack of detail regarding selective dorsal rhizotomy surgery addition to new WHSSC services. Children that undergo this surgery require intensive rehabilitation post operatively as per a protocol for several months (attending physiotherapy twice weekly). Lack of detail regarding additional funding to support this locally for health boards. Funding for this surgery would need to include funding for post-op rehabilitation (physiotherapy) across Wales.	Thank you for your comment. We have not made a change to the document but a commissioning policy is in the process of being drafted and will be explicit in the scope of WHSSC's commissioning of this service.
23	Cardiff and Vale UHB	General			A lack of specific funding for post-op rehab would impact on existing RCTs and service delivery. There is a general lack of dedicated funding for these posts for training needs. Training needs are currently met through local budgets – which is unsustainable and inequitable. Funding for staff to attend specialist conferences, and training events in order to network and maintain their highly specialised skills should be included in budget planning.	Thank you for your comment.
24	Children, Young People and Family Health Services	17		2.1.1	Has any consideration been given in growth estimates of individual Health Boards to the Local Area Development plans. Huge growth in housing in Cardiff in particular	Thank you for your comment, as we commission services on behalf of the population Wales we have considered whole population rates.
25	Children, Young People and Family Health Services	41		3.1	Respiratory Services. UHB already care for children at home on LTV , significant input required by community nursing teams – if this is to be defined the whole pathway elements are essential.	Thank you for your comment, the design and delivery of the specialised respiratory elements of the new service will be considered through the implementation phase. We recognise the barriers of commissioning only the specialised elements of the service as considered in the chapter 7, constraints.
26	Children, Young People and Family Health Services	65	SO2-7	6	Whilst this point is clear it does not reflect the fact that it assumes local services have capacity to support when in actual fact they are already struggling to deliver core services and significant capacity gaps are identified	Thank you for your comments, throughout the development of the strategy we have recognised that the success of a number of the objectives are linked with local provision which is outside of the remit of WHSSC and strategy. We have referenced the constraints in Chapter 7.
27	Children, Young People and Family Health Services	70		7.1	Variation in local services are significant. If Specialist services are to deliver as set out this cannot be ignored and the whole pathway for specialist services needs to be understood. AS re respiratory services, community services cannot deliver on specialist care pathways without being seen as part of that pathway.	Thank you for your comment.
28	Cardiff and Vale UHB	35-38	1	Table 3	The table does NOT include any details on investment in Paediatric Nephrology	Thank you for your comment, this table highlights new investment in services through the WHSSC ICP process since 2015/16, it is caveated that existing contract and contractual uplifts have not been included.
29	Cardiff and Vale UHB	59	6&10	Theme 7	Provision of services of specialised pharmacist (one who can prescribe) for specialised paediatric services like paediatric nephrology is highly essential-Children with chronic kidney diseases and renal transplants need multiple long-term medications. They need repeat prescriptions, close monitoring, parents spend long time waiting for prescriptions, impacts parking at UHW, children miss school, parents miss work, they travel long distance to collect these medication (which often are dispensed only in regional unit) and there are inherent supply issues (Brexid and war not helping). Having a dedicated specialised pharmacist can streamline the process, make it easy for parents, children miss school less often leading to better patient/parent experience. There is a successful model run by pharmacy in adult renal transplant services.	Thank you for your comment, the multi-disciplinary team will vary dependent on the sub-specialty and national standards. The essential members of the MDT for each service will be considered through the development of each service specification.
30	Cardiff and Vale UHB	66	19-35	Strategic Objective 4	'seamless transition' on the contrary need resources if it is intended to be successful. Selected teenagers waiting to be transitioned (those with a chronic illness) need proper assessment by psychology and social worker, to plan for individualised transition strategy. Not paying attention to these aspects and not individualising transition strategies are the reasons why it often fails, the implications are huge for the family. We got to have adequate relevant resources for successful transition.	The essential members of the MDT for each service will be considered through the development of each service specification.
31	Cardiff and Vale UHB	General			Could I draw your attention to service areas where professionals were funded by charities over the last decade-Psychologists and social workers belong to this category and they have been integral to many services including paediatric nephrology. Our service delivery (paediatric nephrology) has been suffering because of the above issue where the above posts disappeared once the charity funding ceased. I have brought this to WHSSC attention multiple times and we are still waiting for this to be resolved.	The essential members of the MDT for each service will be considered through the development of each service specification and subsequent service design. WHSSC has communicated to providers that prior to any charity post appointments
32	Cardiff and Vale UHB	36		Paed endo	To stabilise a small service with full MDT to align with standards. - in process of submitting SBAR regarding difficulties arising as a result of 2019/20 investment (after previous meeting with WHSCC) Continue to be unable to meet all standards. (no service for skeletal dysplasia's secondary osteoporosis)	Thank you for your comment, the SBAR will be considered through implementation phase of the strategy.

Comment number	Name of stakeholder organisation / individual	Page No.	Line Number	Section	Comments	WHSSC response
33	Cardiff and Vale UHB	52			To develop a 5 year commissioning strategy for the provision of high quality, sustainable and equitable specialised paediatric services for the children of Wales – we are somewhat behind in several areas. No mention in this document about level 4 obesity services – there are now specialised obesity clinic is NHS England (complications form excess weight CEW) – this is often the teams that see type 2 diabetes have access to specialist mdt and in patient units and bariatric surgery – no equivalent for wales –appreciate many healthboards still do not have level 3 services in place – but WHSCC would need to commission level 4. Type 2 diabetes far more aggressive in adolescents than in adults – specialist expertise and pathways to ensure all patients have access to tertiary level care (as each healthboard low numbers and so get forgotten0 – in line with wellbeing of future generations	Thank you for your comment.
34	Cardiff and Vale UHB	66		SO4-1	When developing new service specifications or reviewing current ones, the access criteria, the pathway into and out of specialised services and the transition pathway into adult services must be included. No resource anticipated. No uplift to transition services in previous investment – at present our “transition ” relies on goodwill of our adult colleagues – we have 4 clinics scheduled per year for general endocrine and the waiting list is increasing as our clinical activity has increased. – to have a transition process as recommended in standards would require investment to ensure time in adult colleagues job plans in order to follow a transition model.. This is therefore unlikely to be cost neutral if a robust sustainable transition service is to be developed. This required for general endocrine transition as well as for our adolescent gynaecology clinics and metabolic bone clinics.	Thank you for your comment. The access and exclusion criteria, transition arrangements and essential members of the MDT for each sub-specialty are elements of all WHSSC Service Specification. The investment available within the WHSSC remit is for the commissioned elements of the pathway only. The local provision at DGH level is the responsibility of individual Health Boards.
35	Cardiff and Vale UHB	48	1	3.5 Summary Of Issues From The Surgery In Children Work-Stream	There are 4 Key documents that recommend future configuration of surgical services for children. Within these documents there is a clear requirement for a fully resourced, dedicated Acute Pain Service to meet the needs of Children within specialist centres. C&VUHB, currently does not have such a service. There is an Adult Acute Pain Service that provides limited support for children undergoing surgery. A significant consequence of limited paediatric service provision relates to clinical risk. There is no acute pain provision for children with haematological and oncological conditions. No provision is provided for Oncology, patients with sickle cell disease in crisis or for patients experiencing mucositis. A recent Peer Review of Oncology Services within C&VUHB identified the lack of a Paediatric Pain Service as a serious failing. There is also no service provision for children suffering from pancreatitis and only limited provision for patients under the newly commissioned services of elective orthopaedic surgery and spinal surgery (limited to immediate post-operative period). This provides an inequitable service and certain groups of WHSSC Commissioned patients are being disadvantaged. There is also a disparity between the level of care they receive as a child to what they would receive when they transition to adult services (fully resourced, 24 on-call provision, MDT Acute Pain Service). It is imperative that in order for service provision to be appropriate, equal and fair across all WHSSC commissioned specialities and for clinical risk and clinical governance issues to be consistently addressed and managed, a dedicated, fully	Thank you for your comment, the acute pain service was not raised as a priority area by the Collective Commissioning Group whose remit was to consider the current list of WHSSC commissioned services.
36	Cardiff and Vale UHB	54		Strategic Objective 5	In order to provide optimum and timely access to Acute Pain Management for Children and to deliver an equitable service that meets the demand, there needs to be a pain management model with a full MDT, 24 on-call provision in order to align with Royal College of Anaesthetist Standards (as supported within this document)	Thank you for your comment. The acute pain service was not raised as a priority area by the Collective Commissioning Group whose remit was to consider the current list of WHSSC commissioned services.
37	Cardiff and Vale UHB	General Paediatric ID and Immunology		Table 3 (p37)	Please advise ASAP on how to start the process for working up the Paediatric Infectious Diseases (ID) service, so that urgently required funding can be released and appointments made timely to start in year 2 (April 23). As per 3.1 this will require joint planning with Paediatric Immunology (IMM) services.	Thank you for your comment, we will be in contact once the strategy has been approved and the implementation board established.
38	Cardiff and Vale UHB	P42, P57-59, P71		Section 3.1 (p 41)	Tertiary Paediatric ID (unfunded) and Paediatric Immunology are fragile services, delivered from CAV UHB by 3 consultants who are all within ~ 5 years of retirement. This makes succession planning our highest priority. An HEIW commissioned training post does not exist, and is not imminently planned for at either GRID or special interest – SPIN- level. Several high calibre Welsh Trainees are keenly interested (start date required March 2023). Whilst we have the training expertise and clinical material, without post we cannot apply to CSAC even for SPIN level training approval. We would therefore welcome an urgent conversation with our commissioner regarding innovative workforce solutions reflecting the needs of our small specialty, e.g. WHSSC funding of a Clinical Fellow post in Paediatric IMM/ID, to support the service, and as/when required allow Welsh trainees to rotate into (via an out of program for training arrangement with HEIW) with external recruitment at other times.	Thank you for your comment, the existing arrangements for Paediatric Infectious Diseases are currently not commissioned by WHSSC and therefore existing infrastructure and workforce discussions are the responsibility of the local Health Board.
39	Cardiff and Vale UHB	P42, 45		SO1.4 (p 63)	Paediatric ID and Immunology have extensive interdependencies with all medical, surgical and laboratory services. A large proportion of our workload is consultation (in house and across South Wales). We urgently need but currently do not have digital solutions for recording this MDT network activity and flow (e.g. cross health board e-referral, e-advice etc.) to inform our service development in a data driven manner.	Thank you for your comment, the existing arrangements for Paediatric Infectious Diseases are currently not commissioned by WHSSC and therefore existing infrastructure and reporting process are the responsibility of the local Health Board.
40	Swansea Bay UHB	General			Scope of strategy <ul style="list-style-type: none">• For transition – is this at 18 or 25 years of age?• No reference to children with Additional Learning Needs - Additional Learning Needs and Educational Tribunal (Wales) Bill easy read (gov.wales)• Neonatal and Mental Health should be included in the strategy. While there is corresponding work taking place – this strategy has to be for all children, as children with Complex Conditions they don't always fit neatly into one service or another. It will also be difficult to provide tailored care to some children without these areas included• Is there also a need to describe links to maternity services? Commissioning context <ul style="list-style-type: none">• There is some information on birth rates and population to be covered, but nothing on need including how that might be expected to change and how that will impact on the commissioning of services.• What about children in care/look after children and the role of Local Authorities as corporate parents – is there a need to make reference• Does the proposed commissioning relationship with NHSE take into account the differing commissioning models in place? Measuring outcomes and outputs <ul style="list-style-type: none">• There is nothing on outcomes to be expected from the strategy. There are strategic objectives however, all of the actions to support these are processes and nothing about how these would improve the health of the population group.• How is patient and family experience going to be monitored?• Are there any principles for the development of contractual KPIs in place?• For timely repatriation, will there be “two-way” KPIs in relation to expectations/timescales for repatriating children – specifically with NHS Trusts in England. Stakeholder engagement and feedback <ul style="list-style-type: none">• Have any parents/families/children been involved in developing this strategy?• Has the 5 year Specialised Paediatric Services Strategy had any input from partners in Education and Local Authorities – “Health” does not work in isolation• Is there going to be a child friendly version of this strategy developed?	Thank you for your comments. Scope for Strategy From a WHSSC commissioning perspective, transition is ordinarily at the age of 16 years, a position that was supported by Joint Committee (July 2022) for the commissioning and funding of high cost drugs. The WG transition and handover guidance defines children's health services as - The service providing healthcare to the infant, child and young person, including all providers in the primary, secondary, tertiary and community care setting. Children's health services generally care for children up to the 16th birthday. We appreciate that there are clinical and patient considerations to be made. The scope and remit of the project was support by the WHSSC Management Group and Joint Committee prior to commencement. Commissioning Context We have added a sentence in relation to birth rates and projections to provide clarity. We have added the 'NHS Wales Health Assessment Framework for Looked After Children' to Appendix A, that includes all policy and strategic considerations. Measuring outcomes and outputs An Implementation Board will be established following approval of the strategy. The Implementation Board will be accountable to the WHSSC Joint Committee. The remit of the Quality and Governance sub-group was to consider how outcomes and experiences could be measured during implementation of the strategy and beyond, as it is recognised that they are central to the commissioning of paediatric services. The recommendation of the sub-group, which was accepted by the Programme Board was to request all services to report in line with the NHS Wales Quality and Safety Framework (Welsh Government 2021), using the Institute of Medicine (1999) six domains of quality to support a systematic approach, STEEEP. This will ensure that there are robust metrics for measuring experience and outcomes that are rooted within all commissioned services, appreciating that the metric will be specialty specific and therefore will need be phased over the 5 year implementation period. Stakeholder engagement and feedback
41	Swansea Bay UHB	53	1	Strategic Objective 1	It is very important that specialised services are clear about what they do and do not cover, especially at the service proposal stage. In relation to psychological services, a significant amount of work has been undertaken to develop and expand services in order to address unmet need however, it would be beneficial for all Health Boards to work together to develop local maps of specialised services in order to identify gaps and overlaps. Improved communication and collaboration will be key.	Thank you for your comment, we will ensure that these are key considerations during the implementation phase of the strategy.
42	Swansea Bay UHB	53	1	Strategic Objective 2	From a psychological perspective, some specialist services such as surgical services, are suited to having the psychology resource centralised in one Health Board along with the MDT. Other services, particularly those organised around a health condition, which may include cystic fibrosis and epilepsy, will benefit much more from the psychology resource being organised locally and within the Health Board where services can be provided close to home. This is because much of the psychological intervention in these services will involve linkage with the network around the child including school and family. It is pleasing to see this is included in the objective, however, it is important to note that this psychology resource may be best placed being employed by the local Health Board and being part of the child psychology network in that Health Board accessing professional support and governance from local colleagues. This will be important both for ensuring the psychologist is able to perform their tasks well and provide a service close to the child's home through good connections to the local network, and that they are in sustainable and safe jobs with the option for career progression and personal development. Furthermore, this will be important for supporting child psychology departments in all the Health Boards to develop and to recruit locally based qualified psychologist, ensuring an additional benefit to Health Boards, departments and children in the local areas.	Thank you for your comment.
43	Cardiff and Vale UHB	12	¾	Chapter 1	'Establish full MDTs' what do these include or exclude. E.g. Whenever paed care is managed by medicines then pharmacy professionals should be included in the team	Thank you for your comment, the multi-disciplinary team will vary dependent on the sub-specialty and national standards. The essential members of the MDT for each service will be considered through the development of each service specification.
44	Cardiff and Vale UHB	35-37	Through out	Investment in paediatric services	In some parts of the table reference to the MDT does include pharmacy input and sometimes does not. We think the pharmacy team have been successfully included in the MDT in: Oncology, gastroenterology, endocrinology and CF. We want to highlight gaps in investment aims to include pharmacy in the MDT in: rheumatology (missed out of business case so therefore not a full MDT). There are also currently gaps in service to neurology (pharmacy service would not be able to support an increase in Consultant numbers), high dependency and critical care (areas with specialist and high risk medicines). There are national minimum service specifications for PCCU and Nephrology that we currently fall short of. Pharmacy services should not be missed out of specific future investment, including specialised respiratory medicine (outside of CF), infectious diseases (anti-microbial pharmacist resource) and chronic pain.	Thank you for your comment.
45	Cardiff and Vale UHB	57	4	Digital Care	Paediatric Tertiary services consultants are big advocates for electronic prescribing (e-Rx). WHSSC is in a position as commissioner and performance reporting requirements to drive engagement and implementation with the e-Rx agenda. If tertiary services are not driving e-Rx for paed there is a risk systems may not be fit for purpose for this specialist patient group	Thank you for your comments. WHSSC has recently appointed a Medicines Management Pharmacist and we will explore their inclusion within the implementation Board.
46	Cardiff and Vale UHB	59	7	Theme 7	Some re-wording would benefit this section as it could be mis-read as 'Wales needs one Consultant pharmacist to cover all general Paeds, tertiary Paeds and neonates'. In fact each clinical speciality mentioned in point (10) needs to look at their treatments and assess how much medicines leadership is required, then directly employ pharmacy professionals in their team to provide this retaining a great deal of flexibility. Alternate wording:- “Seizing opportunities for workforce redesign and further integration into paediatric teams for pharmacy professionals will increase the rate of service transformation. Due to established career frameworks for pharmacists and soon, pharmacy technicians, these professionals can provide medicines leadership in general and specialised paediatrics and also neonates. Due to tertiary level of services or influence across regional and national geographies in general roles, more posts will be at Consultant Pharmacist level and embedded in clinical teams”	Thank you for your comments, amendments have been made.

Comment number	Name of stakeholder organisation / individual	Page No.	Line Number	Section	Comments	WHSSC response
47	Cardiff and Vale UHB	65	SO 2.4 and 2.7		Support and will require pharmacy input	The essential members of the MDT for each service will be considered through the development of each service specification.
48	Cardiff and Vale UHB		14	2.2	No mention of the commissioned Paediatric Sleep service, however it is referenced on page 41, line 9.	Thank you for your comment, the formal commissioning of 'Paediatric Respiratory' is a clear action within the strategy. There are a number of aspects to this service, only some of which are in receipt of existing WHSSC funding, The proposed plan, subject to support by the implementation board is to commission the tertiary elements of paediatric respiratory including sleep service as one to align with strategic objective 3.
49	Cardiff and Vale UHB	21	3	2.3.1	Cleft Lip & Palate – some complex South Wales CLP patients requiring HDU have surgery in CHfW	Thank you for your comments the illustrations in section 2.3 use information that WHSSC receives on commissioned activity and uses financial year 2019/20 information (pre-Covid-19). In some instances, links may be missing and this is mainly due to insufficient information from providers.
50	Cardiff and Vale UHB	23	10	2.2	Specialised Paediatric Surgery, to note, all General Paediatric Surgery is delivered and commissioned by WHHSC. At the time of resource mapping the secondary care element was not separated.	Thank you for your comment. There is a distinct difference between commissioning responsibility and financial resource mapping. In the instance of paediatric surgery, WHSSC has the commissioning responsibility for specialised surgery and surgery for children who require access to treatment in specialist centre due to the nature of their condition only. As the Children's Hospital for Wales serves the tertiary population and its local population the contract includes specialised and general activity and the risk share reflects this
51	Cardiff and Vale UHB	34	Table 3, row 1	2.4	Paediatric Surgery investment. The funding also supported an additional Consultant sessions and theatre lists.	Thank you for your comment, this section has been amended.
52	Cardiff and Vale UHB	35	Row 1 of table	2.4	Paediatric Clinical Immunology. This has been implemented in part.	Thank you for your comment, this section has been amended.
53	Cardiff and Vale UHB	38	25	3.1	We were surprised not to see any reference to overarching Paediatric Rehab service, and Acute Pain service. Paediatric Acute Pain was highlighted as a serious concern in the recent MTC peer review and Oncology Peer review.	Thank you for your comments, the paediatric rehabilitation will be developed through the implementation phase of the strategy. The peer review documents referenced were shared with WHSSC after the drafting of the documents however the acute pain service was not raised as a priority area by the Collective Commissioning Group whose remit was to consider the current list of WHSSC commissioned services
54	Cardiff and Vale UHB	40	6	3.1	Specialised Paediatric Respiratory. We welcome the inclusion of this into the WHSSC portfolio. Home ventilation is not funded in its entirety. We have funding for the provision of a ventilation fund to purchase equipment centrally, but no provision to deliver a home ventilation service. Sleep has been funded by WHSCC but fallen short of funding. The service that we have expanded without further funding and has increasing waiting list and waiting times. All paediatrics managed within the respiratory team are tertiary. We receive very few GP referrals since the referrals are all screened by general paediatrics. Approximately 66% of all our referrals are from outside UHW. Those within UHW are almost universally tertiary.	Thank you for your comment, a full review of all historic investment will be undertaken as part of the implementation phase of the strategy.
55	Cardiff and Vale UHB	41	15	3.1	We welcome the inclusion of Paediatric Infectious Diseases.	Thank you for your comment.
56	Cardiff and Vale UHB	41	24	3.1	We support the recognition of specialised HDU.	Thank you for your comment.
57	Cardiff and Vale UHB	41	41	3.1	Chronic Fatigue. There is no formal commissioned service at Health Boards for Chronic Fatigue.	Thank you for your comment.
58	Cardiff and Vale UHB	43	19	3.2	Development of services and HB engagement. Agree and recent developments have seen better communication and engagement across Health Boards.	Thank you for your comment.
59	Cardiff and Vale UHB	46	21	3.3	Taking into account the standards specific to the speciality	Thank you for your comment.
60	Cardiff and Vale UHB	49	27	3.5	Networked approach. Further information required on how this would work.	Thank you for your comments, the operational arrangements required to deliver against the strategic objectives will be considered through the implementation phase.
61	Cardiff and Vale UHB	50	3	4.3	Objective 1 – repatriation out of tertiary services when clinically appropriate is a key to success	Thank you for your comment, as noted within section 4.3 clear access routes in and out of specialised services will be included within the specialised services strategy.
62	Cardiff and Vale UHB	53	1	4.3	Linked to above point ensuring local DGH have appropriate skills.	Thank you for your comment, the skill set of staff at local DGH level is outside of the remit of the strategy however we have recognised the link to the success of the strategy in the constraints section (chapter 7).
63	Cardiff and Vale UHB	53	19 – 23	4.3	Agree with this point regarding wider MDT, specifically therapies.	Thank you for your comment.
64	Cardiff and Vale UHB	53	24-25	4.3	Equitable waiting times for all patients through the management of waiting lists by the commissioned provider regardless of the place of delivery. Whilst agree in principle to ensure equitable access this will have a significant resource impact within CHfW and the practicalities need to be worked through	Thank you for your comment, we agree and will ensure this is a thorough consideration at implementation phase.
65	Cardiff and Vale UHB	53	27-29	4.3	Assume this means the secondary care impact of tertiary patients in a tertiary centre will be recognised and funded.	Thank you for your comment, funding arrangement will be for commissioned elements of the service only. The remit of these service will be developed at implementation phase.
66	Cardiff and Vale UHB	54	44812	4.3	Transition – 16-18. WG interpretation v WHSSC. Issue regarding lack of access to adults from Paeds for some tertiary paediatric services that are not WHSSC commissioned for Adults.	Thank you for you comment, the transition criteria for all commissioned services is a standard element of WHSSC service specifications. All new and existing service specifications will be reviewed through the implementation phase.
67	Cardiff and Vale UHB	57	31-36	5.2	Linked to previous comment 14 and 15. There is limited expertise in complex management, care of tracheostomy, PN as examples	Thank you for your comment, we recognise the skillset of local staff is key in achieving timely repatriation, particularly of complex patients.
68	Cardiff and Vale UHB	58	5	5.2	Whole children's hospital - does this mean across whole of Wales?	Thank you for your comment, a key focus of the strategy is to make the best use of resources, both staff and money, in delivering the best quality care possible for children. The development of a children's services workforce strategy for Wales is key in supporting this but is outside of WHSSCs remit. Having a workforce strategy from commissioned providers that sits beneath this is a key element in ensuring the successful delivery of the strategy for the population of Wales
69	Cardiff and Vale UHB	58	9	5.2	Agree, Psychology services is a good example	Thank you for your comment.
70	Cardiff and Vale UHB	59	7	5.2	Agree, pharmacy provision is currently not equitable across specialities.	Thank you for your comment.
71	Cardiff and Vale UHB	61	1	5.5	Development of a structure. Assume cover community, secondary and tertiary? How managed, by whom and to who?	Thank you for your comment, as noted we agree the remit of the overarching structure would include all elements of the pathway and therefore outside of the remit of WHSSC.
72	Cardiff and Vale UHB	63	11 (S01-1)	6	Respiratory - Need a clear understanding what is funded versus what is delivered. Clear service specification required. Could this be considered across year 1 and 2 recognising immediate and medium-term requirements.	Thank you for your comment. We will consider the phasing of implementation at the first oversight group to ensure timely and clear resolution.
73	Cardiff and Vale UHB	63	11 (S01-3)	6	Infectious diseases – Could this be considered across year 1 and 2 recognising immediate and medium-term requirements.	Thank you for your comments, due to funding and capacity constraints it is not possible to bring forward any action that requires investment.
74	Cardiff and Vale UHB	64	6 (S02-1)	6	We believe this requires resource. Transition of highly specialised 16-year olds to adult services in DGH that do not have the expertise. Investment required in regional nurses and wider MDT.	Thank you for your comments, the adult services that paediatric patients transition to is outside of the scope of the strategy however we have recognised it is a key consideration of Health Boards.
75	Cardiff and Vale UHB	64	6 (S02-2)	6	We believe this requires resource.	Thank you for your comment, these are anticipated at this stage and if there are changes these will be considered by the implementation group prior to usual WHSSC processes (Management Group and Joint Committee).
76	Cardiff and Vale UHB	65	1 (S02-5)	6	This will have significant resource requirement for the tertiary provider.	Thank you for your comment, we will consider any unintended consequences including financial of each action at he implementation phase.
77	Cardiff and Vale UHB	67	2 (S05-1)	6	We welcome this.	Thank you for your comment.
78	Cardiff and Vale UHB	67	6 (S06-1)	6	Specialised paediatric oversight group. Who are they and how are they funded?	Thank you for your comment, this will be a key consideration of the implementation group. However the aim is to have representation from across all Health Boards to ensure equity.
79	Cardiff and Vale UHB	59		Theme 7 Workforce, Supply and Shape	Whilst it is appreciated that there are huge benefits to the development of a Consultant Pharmacy post the document should be used to promote the role of consultancy posts across all professions and to raise awareness of the successful implementation of therapy leads in specialised areas such as in the Adult and Paediatric Major Trauma	Thank you for your comment, this section is not an exhaustive list or aimed to be specifically about one sub-specialty, it is referenced as an example.
81	Cardiff and Vale UHB	63		Strategic Objective 1	In order to meet the strategic objectives, dietetic resources will be an area that needs investment in paediatric respiratory, chronic pain and high dependency. As part of this investment consideration needs to be given to current local therapy and psychology support provided to these specialised services and shortfalls should be addressed across Wales	The essential members of the MDT for each service will be considered through the development of each service specification. As noted within the strategy the local workforce at DGH level is outside of the remit of WHSSC however is recognised as a key consideration.
82	Cardiff and Vale UHB	66		Strategic Objective 4	Transition is not consistent across all specialised services. Resources should be allocated to a scoping exercise to map this and identify to the Health Boards areas of concern.	Thank you for your comment, transition arrangements for each specialised service is and will be included within all existing and future service specifications to ensure equity.
83	Cardiff and Vale UHB	70		Primary and Secondary Care Infrastructure	It is great to see local therapy and psychology provision acknowledged here as an area to urgently review. A suggestion would be to obtain a baseline of current AHP staffing against the service specifications. In addition to staffing levels, physical space and working environment should be considered.	Thank you for your comment.
84	Higher Education and Improvement Wales	General	General	General	The document has captured discussions in the workforce group	Thank you for your comment.
85	Higher Education and Improvement Wales	6-7	General	Executive Summary	This section explains the chapters well and lists exclusions. There would be benefit in mentioning Palliative Care is excluded – something I had to go and check.	Thank you for your comment, palliative care is not currently a WHSSC commissioned service. Palliative care was not recommended as a priority area by the Collective Commissioning Group whose remit was to consider the current list of WHSSC commissioned services.
86	Higher Education and Improvement Wales	7	8 after table	Executive summary	Change the language to highlight more emphatically that tertiary care commissioning strategy is presented but that it now depends on other strategic organisations co-ordinating their actions in implementation – a call to action.	Thank you for your comments. Amendments have been made to strengthen this area.
87	Higher Education and Improvement Wales	9	5	Contributors	Correct typo to 'Health Education and Improvement Wales'	Thank you for your comment. The error has been amended.
88	Higher Education and Improvement Wales	12	Graphic	Commissioning cycle	Increase size of visualisation. It can only be read on a large screen and when printed off smaller font is illegible.	Thank you for your comment. We have increased the commissioning cycle visual to a whole page.
89	Higher Education and Improvement Wales	15	End	Chapter 1	A number of key documents are mentioned and as the NHS and Social Care Workforce Strategy features strongly in Chapter 5 I wondered if it should be mentioned here. I acknowledge it is mentioned on Page 74	Thank you for your comment, we have considered this suggestion and have opted to remain with the two existing reference points.
90	Higher Education and Improvement Wales	20	5 (may be other places in doc)	Figure 7	Consider talking about Health Boards rather than LHBs, which seems an outdated term in a new publication.	Thank you for your comment. We have replaced "local health boards" and "LHBs" with "health boards" and "HBs"
91	Higher Education and Improvement Wales	23	Visualisations	Chapter 2	Unique visualisations initially seem intimidating, but very informative and demonstrates understanding and level of oversight which is reassuring.	Thank you for your comment.

Comment number	Name of stakeholder organisation / individual	Page No.	Line Number	Section	Comments	WHSSC response
92	Higher Education and Improvement Wales	35-37	Through out	Investment in paediatric services	In some parts of the table reference to the MDT does include pharmacy input and sometimes does not. We think the pharmacy team have been successfully included in the MDT in: Oncology, gastroenterology, endocrinology and CF. We want to highlight gaps in investment aims to include pharmacy in the MDT in: rheumatology (missed out of bid) and that care to neurology, epilepsy, high dependency and critical care (areas with specialist and high risk medicines), still to be addressed in business cases. Also in respiratory medicine (outside of CF), infectious diseases (anti-microbial pharmacist resource) and chronic pain.	The essential members of the MDT for each service will be considered through the development of each service specification and subsequent service design.
93	Higher Education and Improvement Wales	42	Last 2 lines	Workforce workstream	Need to be clear on the role expected of HEIW with providers. HEIW can support the services in areas such as succession planning, workforce planning using workforce information and training. The service (Health Boards) however need to implement these principles, including retention strategies.	Thank you for your comment.
94	Higher Education and Improvement Wales	43	14	Speciality posts	'pockets of good practice' Consider including a case study in the appendix or a supporting technical document.	Thank you for your comment. The specific areas of good practise will be shared with the specialty specific areas through the implementation phase.
95	Higher Education and Improvement Wales	43	27	Development of services	'there needs to be a children's services workforce strategy for Wales', Who is going to do this and is it going to be commissioned?	Thank you for your comment, this is outside the remit of the strategy.
96	Higher Education and Improvement Wales	46		3.4	If there is NW efficiency plan wouldn't there be one in SW to mirror that?	Thank you for your comment, the development of the NW efficiency plan was on the request of the HB prior to the development of the strategy.
97	Higher Education and Improvement Wales	49	7-10	Feedback	The Medical Deanery in HEIW is responsible for General Paediatric Medical Training. However, specialty training is up to Health Boards, Clinicians and services to encourage trainees to specialise in those areas.	Thank you for your comment.
98	Higher Education and Improvement Wales	53	1 onwards	Strategic Objectives	We support the 6 objectives. 2 - mentions the MDT but could the clarification be improved from 'not only consultants', could it be the unique mix of professionals to manage the specialist conditions, e.g. lots of pharmacy input needed e.g. in neuro, but not in Cleft Palate. 3- It needs to be more clearly explained what 'horizontal' and 'vertical' means in this section as not everyone will read whole document (covered on page 58). 4 - transition from paediatric to adult services is mentioned but specialist paed medicines have a high chance of errors at the interface so aswell as secondary care this needs to include community care (community pharmacies) and primary care if GPs are involved. 6 - When it gets to implementation, the performance oversight should include improved medicines management and governance. There is a high risk of medicines errors in this group, leads to readmission/high cost medicines waste. For example shared care agreements being repatriated from GPs for multiple reasons including medicines costs require monitoring/more secondary care Non-medical prescribers.	Thank you for your comments, further clarification has been provided for the vertical and horizontal commissioning arrangements. It is felt all other comments are operational and will be considered through the implementation phase.
99	Higher Education and Improvement Wales	57	4	Digital Care	Digital consultations are mentioned, but what if the necessitate a prescription (Rx) change? This switch to electronic consultations needs to go hand-on-glove with electronic prescribing, otherwise patients still have to chase around to collect paper scripts. Tertiary services consultants are big advocates for e-RX. WHSSC is in a position as commissioner and performance reporting requirements to drive engagement and implementation with the e-Rx agenda. If tertiary services are not driving e-Rx for paed there is a risk systems may not be fit for purpose for this specialist patient group.	Thank you for your comments. WHSSC has recently appointed a Medicines Management Pharmacist and we will explore their inclusion within the implementation Board.
100	Higher Education and Improvement Wales	57	21	5.2 Workforce	Change Higher Education Wales to 'Health Education and Improvement Wales'	Thank you for your comment. We have corrected this.
101	Higher Education and Improvement Wales	57	General	5.2 Workforce	We naturally support the format of the 7 workforce themes being followed and the content included under each	Thank you for your comment.
102	Higher Education and Improvement Wales	59	7	Theme 7	Pharmacy is a good example of how to redesign services. The corporate support offered by 'pharmacy departments', is insufficient to meet the needs of tertiary Paeds services and requires pharmacy professionals to be embedded in the clinical speciality team, probably co-located. Some re-wording would benefit this section as it could be mis-read as 'Wales needs one Consultant pharmacist to cover all general Paeds, tertiary Paeds and neonates'. In fact each clinical speciality mentioned in point (10) needs to look at their treatments and assess how much medicines leadership is required, then directly employ pharmacy professionals in their team to provide this retaining a great deal of flexibility. Alternate wording:- "Seizing opportunities for workforce redesign and further integration into paediatric teams for pharmacy professionals will increase the rate of service transformation. Due to established career frameworks for pharmacists and soon, pharmacy technicians, these professionals can provide medicines leadership in general and specialised paediatrics and also neonates. Due to tertiary level of services or influence across regional and national geographies in general roles, more posts will be at Consultant Pharmacist level and embedded in clinical directorates to retain flexibility."	Thank you for your comments, amendments have been made.
103	Higher Education and Improvement Wales	65	SO 2.4 and 2.7		Support and will require pharmacy input	The essential members of the MDT for each service will be considered through the development of each service specification.
104	Higher Education and Improvement Wales	66	SO 3.1		There may be a role for HEIW to work along Health Boards here, though it is not currently included in the HEIW workplan.	Thank you for your comment.
105	Higher Education and Improvement Wales	67	SO 6.7		Quality metrics should include some detail around medicines access/supply/costs where they are a major part of treatment	Thank you for your comments. WHSSC has recently appointed a Medicines Management Pharmacist and we will explore their inclusion within the implementation Board.
106	Higher Education and Improvement Wales	71	19	7.2 Workforce	There may be a role for HEIW to work along Health Boards here, though it is not currently included in the HEIW workplan.	Thank you for your comment.
107	Higher Education and Improvement Wales	77	32	Membership	Head of Pharmacy Workforce Planning at HEIW could be added	Thank you for your comment, this specific annex is the membership of the programme strategy that developed the strategy. We would welcome HEIW involvement in the Implementation Board.
108	Dr Julian Raiman Honorary Consultant Inherited Metabolic Disease Paediatric Inherited Metabolic Disease Team, UHW, C&VUHB	30		2.3.12	"... There is flow to Manchester and Salford which is expected for patients with the more rare conditions requiring access to high cost Enzyme Replacement Therapy..." We believe the wording here is confusing and suggest the following "..There is flow to Manchester and Salford which is expected for North Wales. Patients with the more rare conditions requiring access to high cost Enzyme Replacement Therapy will be treated through the respective IMD service dependent on geographical location." This change would highlight that Enzyme Replacement and other novel therapies for example can be delivered by CAV/UHW by the IMD team for families in our catchment area without the need to go to Manchester and Salford.	Thank you for your comment, this section has been amended.
109	Dr Julian Raiman Honorary Consultant Inherited Metabolic Disease Paediatric Inherited Metabolic Disease Team, UHW, C&VUHB	37		2.4/table 3	"Due to a joint model with NHS England, investment in nursing and dietetic infrastructure at C&V UHB.- Implemented in full." We have an ongoing need for support in allied roles and would seek funding to support Psychology and Physiotherapy support within the team. Specifically for Psychologist at a level of 8a/3 days/week and a Physiotherapist between 0.2-0.4WTE to provide ongoing/future support for our patient population beyond 21/22.	Thank you for your comment, a full review of all historic investment will be undertaken as part of the implementation phase of the strategy.
110	Dr Julian Raiman Honorary Consultant Inherited Metabolic Disease Paediatric Inherited Metabolic Disease Team, UHW, C&VUHB	General	General		With regard to Newborn Screening for metabolic disorders and the clinical support the team provides, this isn't covered in this current proposal. We are in current discussion about a change in referral pattern under the new organisation of IMD in C&VUHB. Such that the IMD team will directly receive these referrals of a positive screen first and then coordinate the ongoing care with the local team, rather than the referrals going direct to local paediatric services.	Thank you for your comment, a full review of all historic investment will be undertaken as part of the implementation phase of the strategy.
111	Aneurin Bevan UHB				Overall concern is the impact continued development of tertiary services have on local delivery either in terms of repatriation or local follow up. We are often not funded /commissioned to provide this service and this in turn continues to put pressure on to local services both in terms of workforce and finances. We also have not necessarily had the opportunity for the local workforce to develop the skill set to support care closer to home . (Occupational Therapy) Throughout there is mention of MDT but very limited specific AHP (SLT) reference. The WHSCC Commissioned services that have a direct impact on SLT are Cleft Lip and Palate, BAHA and Cochlear (Both currently have commissioned SLT as part of their MDT). ABUHB SLT has strong and well-established links with both these WHSCC services. It is essential that all new/ renewed WHSCC services have the required highly specialised SLT as a component of their care pathway. For all other pathways particularly Paeds neurosurgery, Paeds ENT, Paeds Neurology where there is a likely speech, language and/ dysphagia there needs to be robust clinical pathways, with transfer protocols in local HBs. Currently there are no acute inpatient Paeds services for children that are transferred back to specialist inpatient care (GUH) Any new services will need to consider impact on local SLT provision as children requiring specialist services have a high clinical need and require intensive rehabilitation with AHPs. Therapy only noted on page 75. (Paediatrician Comment) I am concerned about epilepsy, Neurodisability specialised services, and also transition for children with complex health needs. I would advocate for the needs of those CYP more strongly. I am aware a term of 'complex epilepsy' which I am hearing maybe just in ABUHB, and it is not a term I hear about in PET courses with the BPNA. There is drug resistant epilepsy and there is co-morbidity with epilepsy, which in secondary care should be managed holistically ideally to be frugal with resources. Epilepsy referrals come from acute services (and the youngest patients presenting here will inevitably have co-morbidity at a later stage and often DRE), they also come from primary care (the less worrying absences for example, which do not present to acute services) and in patients on existing consultant case-loads. All are under the CENS team. It is important to provide equitable services for patients with ASD and LD who develop epilepsy also. And of course the most challenging of the group in terms of management are those with drug resistant epilepsy. This all needs thinking about in terms of service provision and models and how they interrelate and sit within the whole service, acute and community. To break up different aspects of health care needs is not child centred, inefficient and wasteful of resource. In secondary care, specialised services have a different meaning and a need for different level of expertise than in tertiary care.	Thank you for your comment, secondary care provision outside of the remit of WHSSC and therefore the strategy. Chapter 7 highlights the constraints of local provision to the potential delivery of the strategy. The essential members of the MDT for each service will be considered through the development of each service specification and subsequent service design. Service specific comments will be managed at implementation phase.

Comment number	Name of stakeholder organisation / individual	Page No.	Line Number	Section	Comments	WHSSC response
112	Aneurin Bevan UHB	22-34		2.3	<p>Many of the illustrations demonstrate equitable use of the tertiary services, e.g. .1, .3,.8,.14, .15. Others suggest that the tertiary service is providing a substantial secondary service to C&V e.g. .4,.7,.9,.10,.13,.17. Should the funding model therefore reflect usage rather than per capital population, to enable funding of adequate secondary care provision within DGHs.</p> <p>This has resulted in distortions of secondary care such that there has been a recruitment of 2.6WTE in ABUHB to service the ECHO need, 2.8 WTE with a neuro/epilepsy lead, 5 consultants contributing to endocrine diabetes with a need for a consultant SPIN training to meet need, there are 3 consultants contributing to respiratory disease and a SPIN gastro consultant, with their associated teams and a nephro/rheum lead with no equivalent in C&V. WHSSC appears to fund the provision of DGH Paeds in C&V to a significant extent.</p> <p>While keen to support tertiary services, how to ABUHB ensure that we are not providing to meet the underfunding of secondary care in C&V, evidenced by the above, when we support respiratory, infectious diseases, radiology, ophthal as mentioned on page 70.</p> <p>This leads to the incidental observation on the data in this section regarding BCUHBs usage of tertiary services which seems to be extraordinary relative to other HBs illustrated in sections .6 and .11. Perhaps this relates to the way the data is captured in England relative to Wales. Not covered in N Wales section Section 3.4 p46</p>	<p>Thank you for your comment, the recruitment of posts at secondary care level is outside of the remit of WHSSC and the strategy.</p> <p>The utilisation of services is closely monitored against access and exclusion criteria, the contribution made by Health Boards to WHSSC contract lines is calculated on a risk share of utilisation.</p>
113	Aneurin Bevan UHB	35-38		2.4 table 3	<p>Some of the models which were set up have suffered some recruitment issues since their creation such that they have degraded. There have been appointments of non-tertiary colleagues to make up service delivery in the CF and endo teams. There was a big delay in the appointment of a second rheumatologist which threatened the sustainability of the service. The neuro-rehab have lost their valuable psychology support. The gastro service is not pan-SWales at present with no inreach into ABUHB, and very asymmetrical service. Paeds cardiology has struggled to tackle the in-equity of provision which has impacted on Gwent patients over an extended period of years. It is important therefore to ensure that the mechanisms behind the assurances for WHSSC are functional and note inequity and then address it, as mentioned in section 4.2</p>	<p>Thank you for your comment.</p>
114	Aneurin Bevan UHB	40-1		3.1	<p>Agree with the priorities, tertiary allergy has not been included however, drug allergy esp anaesthetics</p>	<p>Thank you for your comment.</p>
115	Aneurin Bevan UHB	43			<p>Strongly agree there needs to be a whole workforce strategy, with influence at board and divisional level to protect allied areas e.g. general paed surgery and anaesthetics, orthopaedics etc. for succession planning, and with the paed directorates such that there are SPIN leads or nominees in all services including C&V with appropriate support to deliver services, with the intent of keeping CYPs in secondary care.</p>	<p>Thank you for your comment.</p>
116	Aneurin Bevan UHB	47			<p>Has a Specialist Paeds neuro MDT been established? (SLT)</p>	<p>Thank you for your comments, as noted on page 39 investment has been provided for a Paediatric Neurology MDT however phase 1 has been implemented in part with the business case for phase 2 in progress.</p>
117	Aneurin Bevan UHB	48			<p>The GIRFT strategy actually lifts the age of transfer to specialist services to under 5, so pushes slightly more work to Cardiff for acute abdo. We support move to more day-case work, there was discussion in the SWP for surgical hubs and cross boundary working to upskill DGH teams, perhaps there needs to at least be a network to develop daycase work across HBs. Is this still an option. Imaging is a challenge, and the same GIRFT document suggests non-radiologist imaging, is this being considered.</p>	<p>Thank you for your comments, the operational arrangements required to deliver against the strategic objectives will be considered through the implementation phase.</p>
118	Aneurin Bevan UHB	50			<p>Craniofacial has seen a shift of opinion offer from Swansea direct to Birmingham which will increasingly show in our referral patterns. The service is quick and responsive however.</p>	<p>Thank you for your comment. The current pathway for craniofacial work is to Birmingham.</p>
119	Aneurin Bevan UHB	52		4.2	<p>Wholly support the principles, esp equitable access which has been challenging, with an apparent Cardiff-centric bias in many specialities as mentioned/evidenced above, and an ABUHB-excluding gastro model.</p>	<p>Thank you for your comment.</p>
120	Aneurin Bevan UHB	54			<p>Ensure commissioning and succession planning for Highly Specialist SLTS/ AHP. Section 7.2 AHP noted – at last (SLT)</p>	<p>Thank you for your comment.</p>
121	Aneurin Bevan UHB	53-55		SO1	<p>Clearly defined will inevitably be fuzzy or have a low threshold for tertiary referral to accommodate a poor inhouse provision in C&V and fluctuating experience in different DGHs so should the funding model reflect the usage of by the different HBs, e.g. ABUHB loses an experienced gastro lead and will therefore utilize proportionately more input from gastro services.</p> <p>Development of services – essential that there is engagement and involvement of local HB in developing/ establishing joined up pathways to ensure continuity of care across services.(SLT)</p>	<p>The utilisation of services is closely monitored against access and exclusion criteria, the contribution made by Health Boards to WHSSC contract lines is based on actual utilisation</p>
122	Aneurin Bevan UHB	53		SO2	<p>Really important that there is push-back to DGH of things that should be managed in-house and dividend returned to HBs which pick up a disproportionate about of the tertiary load e.g. endo in ABUHB. There should be a steering network which requires HBs paed directorates to perform to a minimum threshold, that may evolve into cross-boundary mentoring for example or more speciality networking for benchmarking. The job-plan approvals need to encapsulate the noted shortcomings in DGH provision and even a requirement for colleagues to take up additional training to cover shortfalls in provision.</p>	<p>Thank you for your comment the acceptance and refusal criteria for all commissioned services is a standard element of WHSSC service specifications. All new and existing service specifications will be reviewed through the implementation phase.</p>
123	Aneurin Bevan UHB	54		SO3	<p>The contracting needs to acknowledge when tertiary are performing the secondary care role within C&V, and when a HB is overusing provision due to lack of local capacity. While whssc cannot oversee the commissioning of secondary care services, there needs to be a paed network(s) which pushes for services at secondary care level to meet a minimum local capacity.</p> <p>There also needs to be a WHSSC endorsed understanding of ancillary provision, who pays for estate, meet & greet, typing, security etc. within outreach contracting. Who holds the risk for lists, who manages the delivery and performance of those delivering the care where there is marked difference between (tertiary) clinicians.</p>	<p>Thank you for your comments.</p> <p>The access criteria for all commissioned services is a standard element of WHSSC service specifications. All new and existing service specifications will be reviewed through the implementation phase.</p> <p>The operational detail will be considered through the implementation phase, however WHSSC currently only has commissioning responsibility for revenue costs which does not include capital.</p>
124	Aneurin Bevan UHB	55		SO6	<p>There is currently insufficient oversight of tertiary performance, once funded it seems to just role even when there is a drop out of service or striking inequity as mentioned above.</p>	<p>Thank you for your comment. The recommendation of the Quality and Governance sub-group, which was accepted by the Programme Board was to request all services to report in line with the NHS Wales Quality and Safety Framework (Welsh Government 2021), using the Institute of Medicine (1999) six domains of quality to support a systematic approach, STEEEP. This will ensure that there are robust metrics for measuring all aspects of performance that are rooted within all commissioned services, appreciating that the metric will be specialty specific and therefore will need be phased over the 5 year implementation period.</p>
125	Aneurin Bevan UHB	58		Theme 3	<p>P58 – Theme 3 Seamless work models- recognise the need for changes in work models but for these to be successfully implemented clear communication about the proposed model and the requirements of the wider services it impacts on, needs to occur widely. This can impact on staffing requirements and skill mix. Proposed models containing clear patient pathways need to be communicated to all stakeholders. The impact on tertiary services needs to be considered.</p> <p>P58- Workforce supply and Shape- need to recognise importance of retaining skilled paediatric staff in tertiary/community services. Within paediatrics staff often train in tertiary but move to specialist centres due to higher banded posts. Need to retain specialist staff – vital for training/supervision and succession planning. Posts in paediatric specialist centres often higher banding then equivalent role in tertiary/community setting. Need to consider staff equity.</p>	<p>Thank you for your comments, the workforce requirements for all sub-specialty services will be considered through the development of new and review of existing service specifications. All WHSSC Service Specification are developed in collaboration with clinical teams and are subject to formal consultation.</p>
126	Aneurin Bevan UHB	59		Theme 7	<p>Work force supply and shape</p> <p>Would definitely support a constant tertiary pharmacist but also Paeds pharmacy leads, and digital working for prescribing in terms of safety. Surgery and anaesthetics need networking to support DGH skills, may support hub working.</p> <p>Complex needs management might benefit from a different model with a non-consultant keyworker to co-ordinate care, this may feed wel, into transition.</p> <p>What opportunities for integration are being referred to in this section</p> <p>7 day services noted – this will need to planned and funded(SLT comments)</p>	<p>Thank you for you comments.</p> <p>The essential members of the MDT for each service will be considered through the development of each service specification.</p> <p>WHSSC has recently appointed a Medicines Management Pharmacist and we will explore their inclusion within the implementation Board.</p>
127	Aneurin Bevan UHB	60		Theme 8	<p>Work force supply and shape</p> <p>Would definitely support a constant tertiary pharmacist but also Paeds pharmacy leads, and digital working for prescribing in terms of safety. Surgery and anaesthetics need networking to support DGH skills, may support hub working.</p> <p>Complex needs management might benefit from a different model with a non-consultant keyworker to co-ordinate care, this may feed wel, into transition.</p> <p>What opportunities for integration are being referred to in this section</p> <p>7 day services noted – this will need to planned and funded(SLT comments)</p>	<p>Thank you for you comments.</p> <p>The essential members of the MDT for each service will be considered through the development of each service specification.</p> <p>WHSSC has recently appointed a Medicines Management Pharmacist and we will explore their inclusion within the implementation Board.</p>
127	Aneurin Bevan UHB	60		5.4 Capital	<p>There is a capital and estates crisis across s.wales in terms of delivering inreach, outreach and MDT working. Also the ancillary costs need to be factored into commissioning as mentioned above.</p>	<p>Thank you for your comment, capital requirements are outside of the remit of WHSSC.</p>
128	Aneurin Bevan UHB	61		5.5 coordinated structure	<p>This is probably the most important part of the vision, looking at reducing variability, developing meaningful networks of learning and practice, and ensuring that tertiary services sit within a broader provision of equity and quality</p>	<p>Thank you for your comment.</p>
129	Aneurin Bevan UHB	63		So 1.1-4	<p>The difficulty will be to define what is secondary care in all these areas and avoid a push to the centre</p>	<p>The access and exclusion criteria for all commissioned services is a standard element of WHSSC service specifications. All new and existing service specifications will be reviewed through the implementation phase.</p>

Comment number	Name of stakeholder organisation / individual	Page No.	Line Number	Section	Comments	WHSSC response
130	Aneurin Bevan UHB	64		SO2-1	Will need to influence divisional level at a succession planning level (need to know what is planned for the future) to ensure Paeds is provided for at a general level in surgical specialities and anaesthetics and GITU to avoid some of the silos that have caused such angst over the years. This would be to ensure this like MRI, surge management, daycase work, and basic Paeds general surgery/urology don't get referred into centre when someone retires. (acknowledging that Paeds isn't always a pull for generalists, carrying risk and little remuneration). Offer cross-boundary working? P64 - Strategic Objective 2 SO2 1-7 – Need to ensure adequate staffing to facilitate care closer to home, also retain specialist staff/educate staff to ensure skill/speciality. May effect role/JD impact on re-banding.	The access and exclusion criteria for all commissioned services is a standard element of WHSSC service specifications. All new and existing service specifications will be reviewed through the implementation phase.
131	Aneurin Bevan UHB	65		SO2-5	Who holds the waiting list, who is aribitor of equity of access	Thank you for your comments the detail of outreach waiting list management and how this will be operationalised with clear governance will be a consideration at implementation stage.
132	Aneurin Bevan UHB	65		SO2-6	Important obligation to probogate best practice and even out expertise in secondary care through education and network meetings	Thank you for your comment, the skill set of staff at local DGH level is outside of the remit of the strategy however we have recognised the link to the success of the strategy in the constraints section (chapter 7).
133	Aneurin Bevan UHB	66		SO4	Transition is a challenge when there is the equivalent to a paediatrician in adult services, so many conditions would suffer a disservice as there is no equivalent cardio/gastro/neuro/renal etc. person in Paeds equivalent to an adult specialist and there is no generalist except the GP to pick up complexity unless one considers COTE, but there is an opportunity to consider a different professional group of keyworkers who could manage transitioned complex patients	The transition arrangements for each sub-specialty are elements of all WHSSC Service Specification. The investment available within the WHSSC remit is for the commissioned elements of the pathway only. The local provision at DGH level is the responsibility of individual Health Boards.
134	Aneurin Bevan UHB	66			Agree use of professional standards (e.g. Audiology standards) is required to benchmark workforce requirement (SLT)	Thank you for your comment.
135	Aneurin Bevan UHB	72			Agree need to be clearly planned transition from Paeds to adults – resource will be required (SLT)	Thank you for your comment.
136	Cardiff and Vale UHB	54		4	We agree that a combined paediatric and adult MDT approach to deliver a robust transition service would address young people's needs and provide a quality holistic care.	Thank you for your comment.
137	Cardiff and Vale UHB	66		S04-1 S04-2	Implementing clearly defined transition pathways, identifying workforce with specialist expertise and infrastructure to deliver a joint paediatric and adult MDT care for adolescents in children's services transitioning to adult services would need some investment. We think that it is unlikely to be delivered at cost neutrality as stated in this document. We wondered if a working group with MDT professionals interested in improving transition across all WHSSC funded paediatric sub specialities could be developed to address implementation issues for transition care.	The transition arrangements for each sub-specialty are elements of all WHSSC Service Specification. The investment available within the WHSSC remit is for the commissioned elements of the pathway only. The local provision at DGH level is the responsibility of individual Health Boards.
138	Alder Hey Children's NHS Foundation Trust	25		2.3.5	Please note the paediatric pathway for children with CF in North Wales is not to LHCH but to Alder Hey. The LHCH element is for transition	For the purposes of the flow charts it includes the commissioned elements of the service as per the activity returns. We have amended the language in paragraph 2.3.5 to further clarify.
139	Alder Hey Children's NHS Foundation Trust	from page 29		2.3.11	There is no specific mention to the alignment of orthopaedic services with Alder Hey and North Wales other than that in the graphic on page 29	Thank you for your comment. The commissioning arrangements for paediatric orthopaedic services was agreed prior to the commencement of the strategy development. A formal consultation took place on the service specification which included the commissioning arrangements for north Wales.
140	Alder Hey Children's NHS Foundation Trust	34		2.4	Investment Aims – Paediatric Radiology. It would be helpful to understand what this means for North Wales	Thank you for your comment, the paediatric radiology funding was to support the 24 hour services in south Wales with outreach support to upskill at local units.
141	Alder Hey Children's NHS Foundation Trust	46		3.4	AHCH support the statement and welcome remaining closely engaged. We support the principle of care closer to home but with specialist support where appropriate in the patient's pathway.	Thank you for your comment.

DRAFT - 5 year Commissioning Strategy for Specialised Paediatric Services



July 2022

Draft Version 0.17

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Foreword

This 5 year commissioning strategy for specialised paediatric services sets out our ambitious approach to improving equitable access to quality services for the children of Wales.

The strategy is underpinned by WHSSC's ambition to support the bold agenda set out in A Healthier Wales (2018) along with ensuring the Rights of the Child are met. The strategic objectives set out in the document have quality at their core and this will ensure WHSSC can meet demands of the National Clinical Framework for Wales (2021) and the Quality and Safety Framework (2021). Collectively these set out an aspiration for quality-led health and care services, underpinned by prudent healthcare principles, value-based healthcare and the quadruple aim.

We are cognisant that the success of the strategy is dependent on its alignment with Health Board priorities in delivering across the whole pathway, as well as co-ordinating actions and implementation with other strategic organisations and their priorities.

The Strategy has therefore been developed in collaboration with key stakeholders from across NHS Wales and NHS England, and despite the demands of responding to the Covid-19 pandemic we have been supported by dedicated clinical teams, health professionals and managers in progressing this document. The detailed understanding and suggestions for improvements would not have been possible without their continued support.

This draft document is the first step in that process and provides the basis for wider stakeholder involvement and will allow us to capture the views of those children and families accessing the services commissioned by WHSSC. Your input into this draft is therefore essential if we are going to be able to implement a strategy, which truly delivers on the ambitions of A Healthier Wales and delivers the best services possible for the children of Wales, we look forward to receiving your views.

Dr Sian Lewis
Managing Director

Executive Summary

This 5 year Specialised Paediatric Services Strategy has been developed in partnership between the Welsh Health Specialised Services Committee and the 7 Health Boards for whom it commissions services. It aims to convey both the current position for the provision of Paediatric Specialised Services for Welsh paediatric residents, from English and Welsh providers, and to establish the future vision and commissioning intent to ensure high quality services for the children of Wales and their families and carers.

It has at its heart the following strategic aim:

"...to develop a 5 year commissioning strategy for the provision of high quality, sustainable and equitable specialised paediatric services for the children of Wales."

Chapter 1 offers some background to the strategy, and sets it within the policy context of NHS Wales. It provides details on the services that are within the scope of the strategy and outlines how the strategy process has been enabled along with associated governance frameworks.

Chapter 2 presents '**Where we are now**'. It offers information on current service provision, paediatric patient flows and issues that are emerging within Specialised Paediatric services.

Chapter 3 continues the '**Where we are now**' theme by presenting the findings that have emerged through the project group structure, before drawing these together into strategic objectives in Chapter 4.

Chapter 4 sets out the aspiration of the strategy, '**Where do we want to be?**' As such it develops a set of strategic objectives from which a number of key actions are developed:

Strategic Objective 1	There are clear access criteria and routes into and out of tertiary services for Children and their families, with increased knowledge of the remit of specialised services provision and how they fit within the whole pathway of care.
Strategic Objective 2	Children receive high quality, equitable and patient tailored care in the most appropriate environment, whether that be in-reach or outreach, with clinical teams supporting the use of advanced digital technologies and regional education and training.

Strategic Objective 3	A patient centred commissioning model which adds value to the treatment of children, strengthens the whole pathway approach and is commissioned across the horizontal <u>(sub-specialty)</u> and vertical <u>(professional group)</u> delivery of specialised services, supporting the transforming health care agenda within Wales.
Strategic Objective 4	Children and their families experience seamless transition across their care and treatment pathway, and between age related services.
Strategic Objective 5	Specialised Paediatric services are funded prudently to ensure optimum and timely access for children, with priority being given to those services where there are deficits and constraints.
Strategic Objective 6	Health Boards are assured that the commissioning and delivery of specialised services for children and their families have appropriate oversight structures in place.

Chapter 5 outlines '**How we get there**'. It outlines the necessary enablers and implementation arrangements that will be required to ensure implementation of the strategy.

Chapter 6 outlines the '**How we get there**' and sets out the high level actions that are required to meet each of the strategic objectives.

Chapter 7 outlines the '**constraints**' beyond the remit of WHSSC that need to be considered and addressed by Health Boards and other strategic organisations in order to ensure the optimum impact of the strategy.

When developing the scope and remit of the strategy it was agreed that Neonatal and Mental Health would not be included, as two separate strategic pieces (Neonatal Cot Reconfiguration and the Mental Health Strategy) of work are underway by WHSSC.

Contributors

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Further contributions have been received from representatives of the following organisations:

Aneurin Bevan University Health Board
Betsi Cadwaladr University Health Board
Cardiff and Vale University Health Board
Cwm Taf Morgannwg University Health Board
Hywel Dda University Health Board
Powys Teaching Health Board

Swansea Bay University Health Board
Alder Hey Children's Hospital NHS Foundation Trust
Birmingham Children's Hospital NHS Foundation Trust
University Hospitals Bristol NHS Foundation Trust
[Higher Health](#) Education [and](#) Improvement Wales

CHAPTER 1

1.0 INTRODUCTION

The Welsh Health Specialised Services Committee (WHSSC) works on behalf of the seven Health Boards in Wales to commission high quality, sustainable and equitable specialised services for the population of Wales. Services are delivered by Local Health Boards across Wales and NHS providers in England.

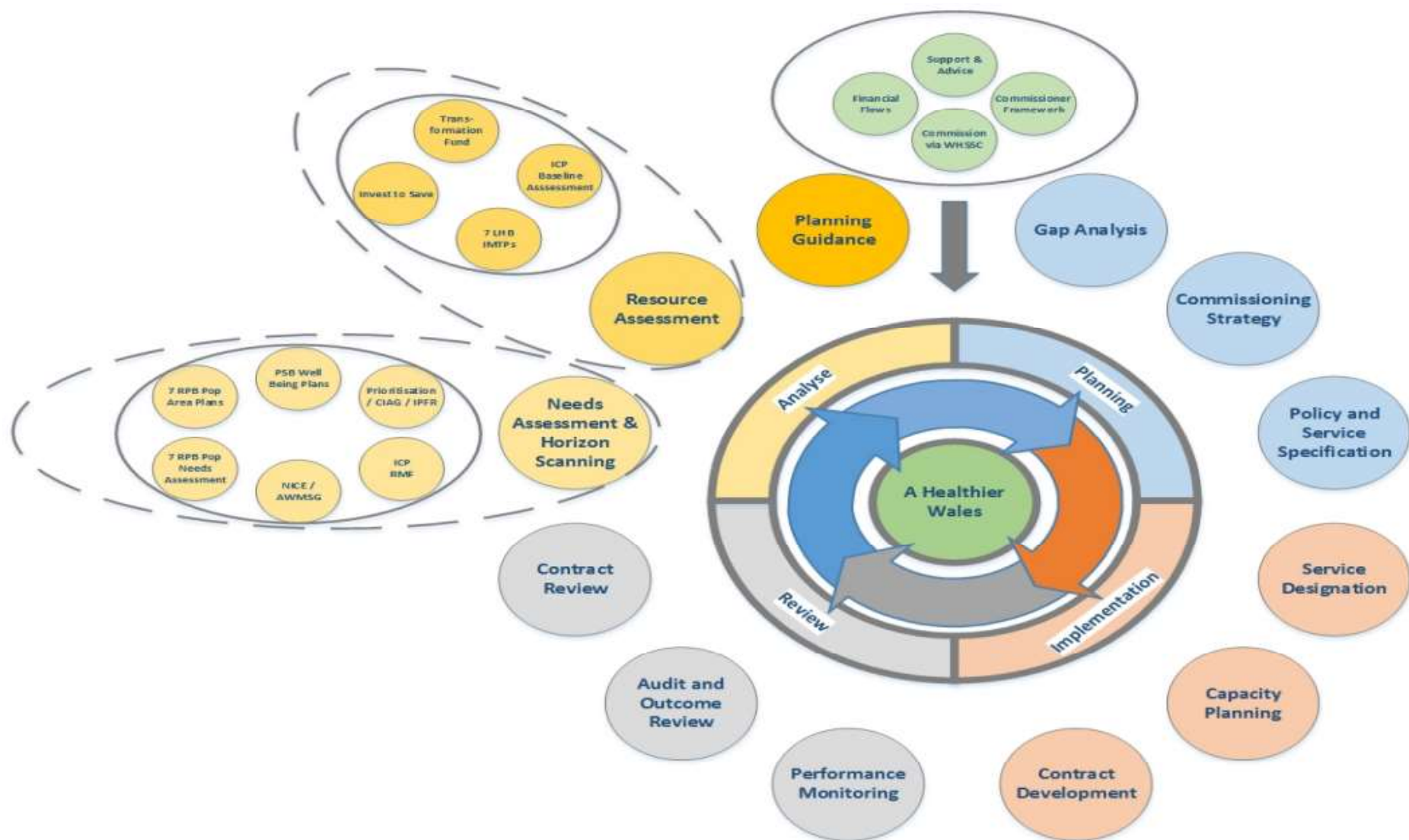
The WHSSC structure is divided into 6 commissioning teams: Cancer and Blood; Cardiac Conditions; Mental Health and Vulnerable Groups; Neurosciences and Complex Conditions; the adult Renal Network; and Women and Children. The Commissioning Teams are multi-professional groups that deliver high-quality commissioning advice for the WHSSC Joint Committee. The Commissioning Teams include the relevant Associate Medical Director, planning, quality, finance and information representatives. This strategy has been developed by the Women and Children's commissioning team through a formal project management structure.

WHSSC's role is to:

- plan, procure and monitor the performance of specialised services;
- establish clear processes for the designation of specialised services providers and the specification of specialised services;
- ensure there is assurance regarding clinical quality and outcomes through the contract mechanisms and a rolling programme of service review;
- develop, negotiate, agree, maintain and monitor contracts with providers of specialised services;
- undertake associated reviews of specialised services and manage the introduction of drugs and new technologies;
- co-ordinate a common approach to the commissioning of specialised services outside Wales;
- manage the pooled budget for planning and securing specialised services and put financial risk sharing arrangements in place;
- ensure a formal process of public and patient involvement underpins its work; and
- ensure that patients are central to commissioned services and that their experience when accessing specialised services is of a high standard.

All of this work is undertaken on a cyclical basis with ongoing engagement with patients, service users and professionals. WHSSC's commissioning cycle is shown in **Figure 1** below:

Figure 1: WHSSC commissioning cycle



1.1 Why do we need a strategy for Specialised Paediatric Services?

Tertiary paediatric services have been in receipt of significant investment through WHSSC processes in recent years. This has, in the main, been to establish full MDTs for specialised services and to stabilise historically fragile services in order to enhance and improve patient care and access. Despite this investment, there remain specific issues for both south and north Wales services. In order to determine the impact of investment and to consider the remaining issues it was considered to be a timely juncture to develop a formalised strategy for Specialised Paediatric Services.

Whilst the focus of this work is on the provision of Specialised Paediatric Services for children in Wales, it is of course set within a wider policy framework as it relates to NHS Wales and the broader Paediatric discipline; to support the health and wellbeing of children. Maximising the outcomes for children from a Specialised Services perspective, accepting it is only part of the pathway, will contribute to the broader system which will improve the social outcomes of children in all areas of their lives in particular health and education. A summary of the key documents that should be considered alongside this strategy is outlined in **Appendix A**.

1.2 The Strategy Governance and Process

In order to develop the Paediatric Strategy a full programme structure was developed. This has allowed for the strategy to be developed in a collaborative way with providers of specialised services and those referring in to specialised services from across NHS Wales and NHS England, with clear and robust governance routes for approval.

Through all stages of the Programme we have applied the following principles¹:

Attended	Throughout all formal meetings of the Programme and informal discussions we have listened objectively to the positive and negative experiences and frustrations felt by colleagues across NHS Wales and England.
Understood	The Programme Team has taken the time to understand the detail ensuring all views and evidence have been considered appropriately.

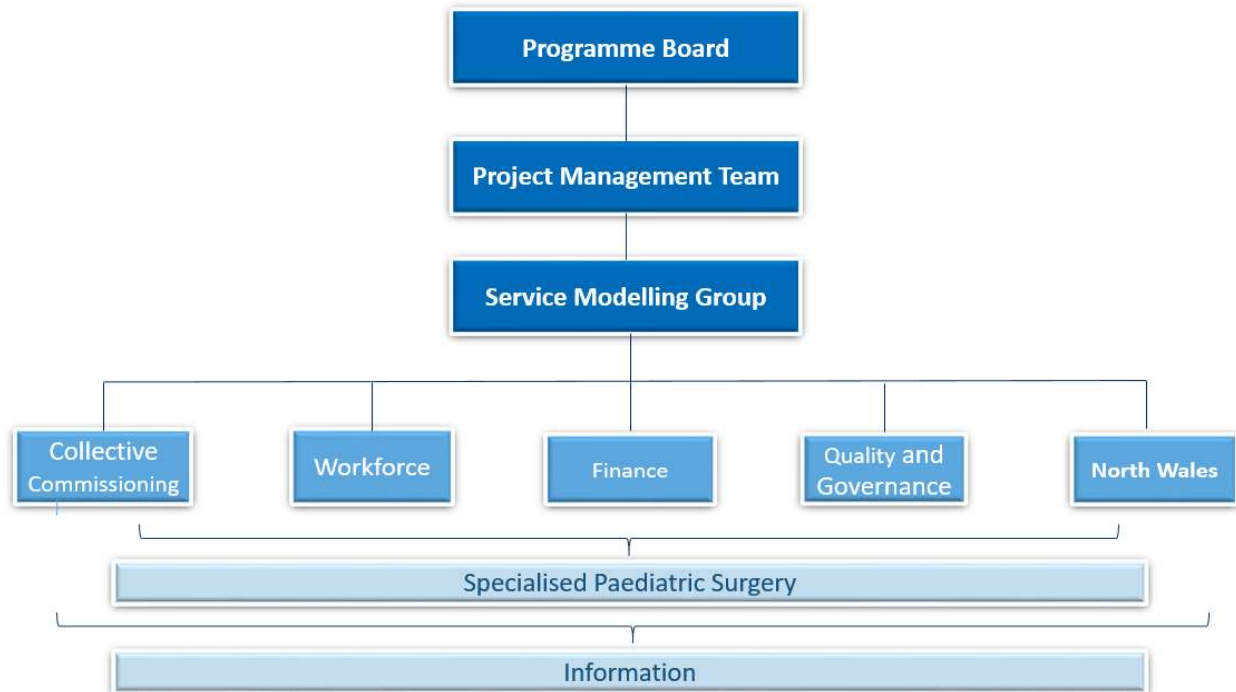
¹ King's Fund – Compassionate Leadership [What is compassionate leadership? | The King's Fund \(kingsfund.org.uk\)](https://www.kingsfund.org.uk/what-is-compassionate-leadership/)

Empathised	Through adopting varying styles such as meetings, workshops and questionnaires it has allowed for colleagues to express frustrations and concerns in an anonymous and safe way with all views being considered empathetically.
Helped	In light of the current pressures of Covid-19 a number of adjustments have been made to the structure of the strategy development in order to assist colleagues in attending and contributing to discussions.
Helping in the Future	Throughout the development of the strategy, moving in to the implementation phase and beyond, a commitment has been made to continue to help. The input and views of others in to the monitoring and development of paediatric services is a continuous cycle of review.

1
2

The programme structure that was established to support the development of the strategy is outlined in **Figure 2** below:

Figure 2: Programme Structure



The aims, objectives and membership of each of the project components can be found in **Appendix B**.

1.3 Rights of the Child

Children and young people have 42 rights under the United Nations Convention on the Rights of the Child (UNCRC). These 42 rights give children and young people what they need to grow up happily, healthily and safely. In 2011 Wales became the first country in the UK to make the UNCRC part of its domestic law. The Rights of the Child have been core to the development of the strategy. A full list of the 42 rights are available in **Appendix C**.

1.4 Future Generations and Wellbeing Act

[The Wellbeing of Future Generations Act \(2015\)](#) puts in place 7 well-being goals:

- A prosperous Wales
- A resilient Wales
- A healthier Wales
- A more equal Wales

- A Wales of cohesive communities
- A Wales of vibrant culture and thriving Welsh language
- A globally responsible Wales

The aim of the Wellbeing and Future Generations Act is to improve the social, economic, environmental and cultural well-being of Wales, to ensure a future and resilient society. There is strong evidence to suggest that 'the wellbeing of women and children will produce a fairer, stronger, and more resilient society'²

² Modi N.,Hanson M. 2021. [Health of women and children is central to covid-19 recovery](#). *BMJ* 2021;373:N899

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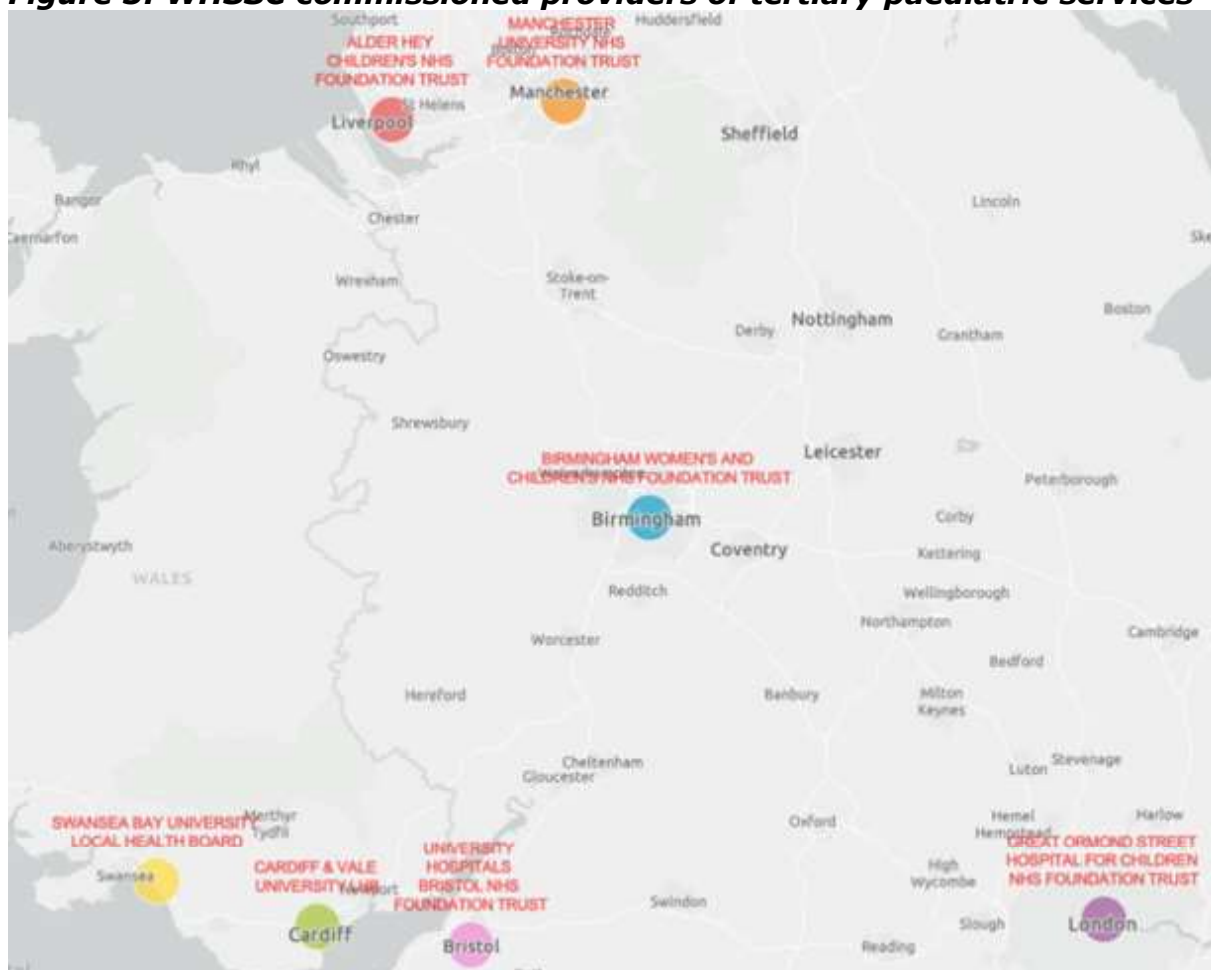
CHAPTER 2

2.0 WHERE ARE WE NOW?

2.1 Current population, projections and commissioned providers

Based on 2020 mid-year estimates³ the paediatric population for Wales is 596,592, which is 18.8% of the total population. To meet the tertiary needs of the paediatric population, tertiary paediatric services are commissioned by WHSSC from a number of providers across the UK (**Figure 3**). The south, south west and Powys population predominantly access tertiary paediatric services from the Children's Hospital for Wales, Cardiff; Bristol Royal Hospital for Children; University Hospitals Bristol NHS Trust; and Birmingham Children's Hospital; with patients from north Wales accessing mainly from Alder Hey Children's Hospital.

Figure 3: WHSSC commissioned providers of tertiary paediatric services



2.1.1 Population size & projections

The following figures include a number of analyses using different data sources to highlight the possible demand for paediatric services over the

³ [Population estimates for the UK, England and Wales, Scotland and Northern Ireland - Office for National Statistics \(ons.gov.uk\)](https://www.ons.gov.uk/populationandcommunity/populationandmigration/populationestimates/articles/populationestimatesfortheukenglandandwalesscotlandandnorthernireland)

next 5 years (to 2026). The projections are based on historical paediatric (0-16 age group) activity, unlike Office for National Statistics (ONS) where there is a complex methodology used to develop their projections.

In some visuals, an ONS projection may be used as a comparison and this is for illustration purposes only as the ONS projections are based on previous years populations, not current, and do not take into account the Covid-19 pandemic. The population data used is a mixture of ONS, StatsWales (Welsh Government), and National Community Child Health Database (NCCHD) for 2020 live birth numbers only.

Figure 4: Population Projections

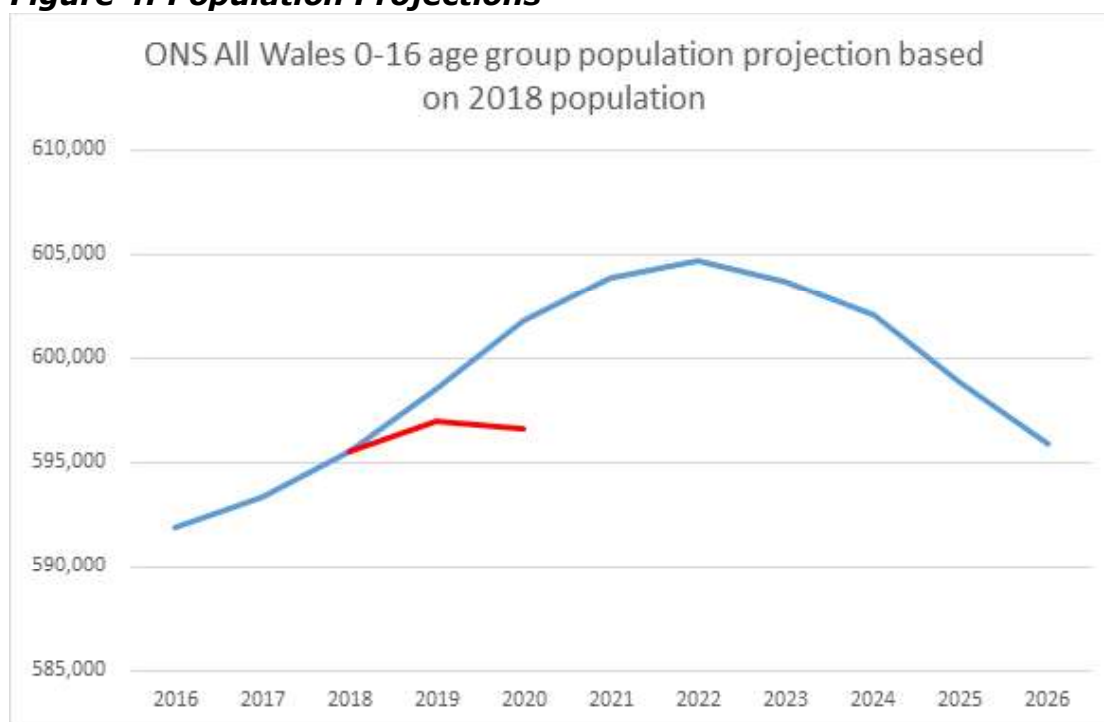


Figure 4 above illustrates the ONS projected trend (blue) of the Children (0-16) population of Wales based on a 2018 mid-year estimate. Also included are the 2019 and 2020 ONS mid-year estimates (red) based on actual historic data to illustrate the actual numbers against the projections. The paediatric population is projected to peak in 2022. However, population estimates based on actual historic data show that the peak may have already occurred in 2019.

Below, in **Figure 5**, a breakdown of the Children ONS population projections (based on 2018 mid-year estimates) by Local Health Board (LHB) is provided. The mid-year estimates for 2020 can be found in **Figure 6**.

Figure 5: Population projections

LHBs	2018	2019	2020	2021	2022	2023	2024	2025	2026
AB	116,783	117,522	118,251	118,758	119,070	119,090	118,984	118,488	117,953
BCU	131,479	131,915	132,563	132,869	132,760	132,215	131,491	130,476	129,522
C&V	96,871	97,454	98,081	98,601	98,898	98,816	98,499	98,010	97,572
CTM	87,213	87,800	88,324	88,805	88,996	88,920	88,857	88,537	88,168
HD	69,509	69,799	69,994	70,064	69,996	69,736	69,365	68,776	68,355
Powys	22,609	22,611	22,671	22,675	22,617	22,561	22,474	22,290	22,141
SB	71,048	71,386	71,860	72,139	72,317	72,383	72,411	72,232	72,149

The projections in **Figure 5** show that the children population continues on an increasing trend through 2018-2020. However, what is found in the population mid-year estimates in **Figure 6** is that all LHBs are on a decreasing trend from 2019-2020. There is little information to support that this is a continuing trend or whether other unforeseen factors are at play to cause this decrease i.e. the recent COVID-19 pandemic.

Figure 6: Mid-year population projections

LHBs	2018	2019	2020
AB	116,783	117,281	117,133
BCU	131,479	131,469	131,131
C&V	96,871	97,432	98,077
CTM	87,213	87,613	87,445
HD	69,509	69,676	69,437
Powys	22,609	22,530	22,489
SB	71,048	70,946	70,880

2.1.2 Birth rates

With live birth projections, the data could not be disaggregated by LHB and the ONS data includes all births, therefore the data used here is live births from 2010 to 2020. Using forecasting functionality in Microsoft Excel, a projection has then been cast based on the historical numbers.

These figures include an upper and lower confidence bound of 95% meaning that 95% of future points would be expected to fall within the radius from the resulting forecast value(s). The 2020 birth number is from National Community Child Health Database (NCCHD).

Figure 7: Live birth projections

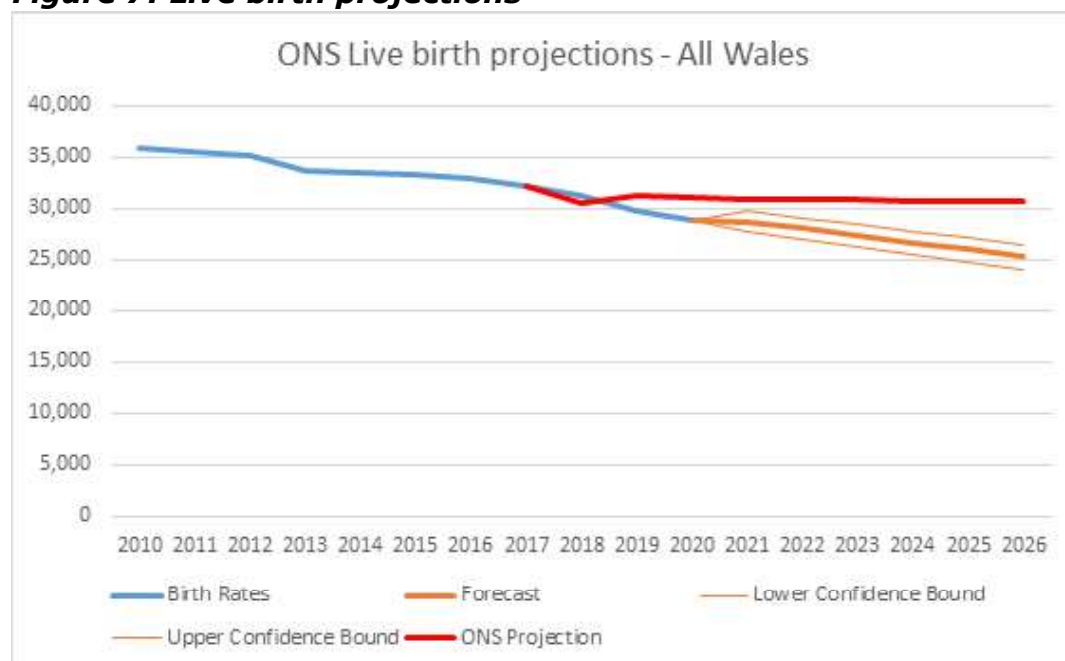


Figure 7 illustrates the trend of actual births (2010 – 2020) and then a projection from 2021 to 2026 based on the actuals. The ONS projection has been added for comparison and includes all births. The actuals for 2018, 2019 and 2020 are on a steeper decreasing line than the ONS projection. ONS projection based on 2018 live births. **Figure 8** contains the LHB split of actual live births to 2020. Together with the forecasts we are seeing a decreasing trend in live births across all LHBs.

Figure 8: LHB split of live births

LHBs	2018	2019	2020	2021	2022	2023	2024	2025	2026
AB	6,206	6,121	5,764	5,868	5,772	5,676	5,581	5,485	5,389
BCU	6,740	6,355	6,173	6,070	5,904	5,737	5,571	5,405	5,239
C&V	5,349	4,939	4,944	4,868	4,735	4,602	4,470	4,337	4,204
CTM	4,703	4,499	4,245	4,289	4,186	4,083	3,980	3,877	3,773
HD	3,362	3,229	3,195	3,135	3,058	2,982	2,905	2,829	2,752
Powys	1,114	1,034	1,018	1,024	1,005	986	967	948	928
SB	3,800	3,527	3,314	3,377	3,283	3,189	3,095	3,001	2,907

2.1.3 Population distribution by Health Board

Based on a 2020 mid-year estimate population for Wales, 188 per 1,000 population are aged 0-16 (which is 18.8%). **Figure 9**, below, presents the distribution of children (0–16) by LHB at a Local Authority level.

Figure 9: Distribution of children (0–16) by LHB at Local Authority level

LHB	Local Authority	Total Population	0-16 population	No. of 0-16 per 100,000
Aneurin Bevan UHB	Newport	156,447	33,851	21,637
	Caerphilly	181,731	35,603	19,591
	Torfaen	94,832	18,500	19,508
	Blaenau Gwent	70,020	12,913	18,442
	Monmouthshire	95,164	16,266	17,093
Betsi Cadwaladr UHB	Wrexham	136,055	27,454	20,179
	Flintshire	156,847	30,546	19,475
	Denbighshire	96,664	18,440	19,076
	Isle of Anglesey	70,440	12,647	17,954
	Gwynedd	125,171	21,974	17,555
	Conwy	118,184	20,070	16,982
Cardiff & Vale UHB	Vale of Glamorgan	135,295	26,406	19,517
	Cardiff	369,202	71,671	19,412
Cwm Taf Morgannwg UHB	Merthyr Tydfil	60,424	12,208	20,204
	Rhondda Cynon Taf	241,873	47,472	19,627
	Bridgend	147,539	27,765	18,819
Hywel Dda UHB	Carmarthenshire	190,073	35,200	18,519
	Pembrokeshire	126,751	22,715	17,921
	Ceredigion	72,895	11,522	15,806
Powys	Powys	133,030	22,489	16,905
Swansea Bay UHB	Neath Port Talbot	144,386	26,634	18,446
	Swansea	246,563	44,246	17,945

As demonstrated in the above figures, there is a forecast reduction in paediatric population rates across Wales, however at this stage it is not anticipated that there will be significant impact on access rates. Access rates and population rates will be monitored throughout the lifespan of the strategy.

2.2 Incidence rates of specific conditions

WHSSC commissions a broad range of paediatric services from highly specialised Bone Marrow Transplants and high cost drugs for Rare Diseases which are funded on an individual patient basis; emergency services including Paediatric Intensive Care and Paediatric Surgery; and specialities providing ongoing care for long term conditions such as Paediatric Rheumatology and Paediatric Endocrinology. A full list of commissioned services is provided in **Figure 10**. Where there is published evidence for incidence rates it has been summarised in **Appendix D**.

Figure 10: WHSSC Commissioned Paediatric Services

Cleft Lip and Palate

Paediatric BAHA and Cochlear

Paediatric Bone Marrow Transplant (BMT)	Paediatric Burns Services
Paediatric Cardiac Surgery	Paediatric Cardiology
Paediatric Clinical Immunology	Paediatric Cystic Fibrosis
Paediatric Endocrinology	Paediatric Extracorporeal membrane oxygenation (ECMO)
Paediatric Gastroenterology	Paediatric Haematology
Paediatric Inherited Metabolic Disease	Paediatric Intensive Care
Paediatric Intestinal failure/ HPN	Paediatric Nephrology
Paediatric Neurology*	Paediatric Neurosurgery
Paediatric Neuro-rehabilitation	Paediatric Oncology
Paediatric Plastic Surgery	Paediatric Radiology
Paediatric Radiotherapy	Paediatric Rheumatology
Paediatric Transplant	Specialised Ear Nose and Throat Surgery
* (including Ketogenic Diet and Epilepsy Surgery)	Specialised Paediatric Surgery

Figure 11 includes three services/treatments which have been added to the WHSSC remit of commissioning responsibility as of 2022/23:

Figure 11: WHSSC Newly Commissioned Paediatric Services/Treatments

Specialised Paediatric Orthopaedic Surgery
Specialised Paediatric Spinal Surgery
Selective Dorsal Rhizotomy (a treatment within Paediatric Neurology)

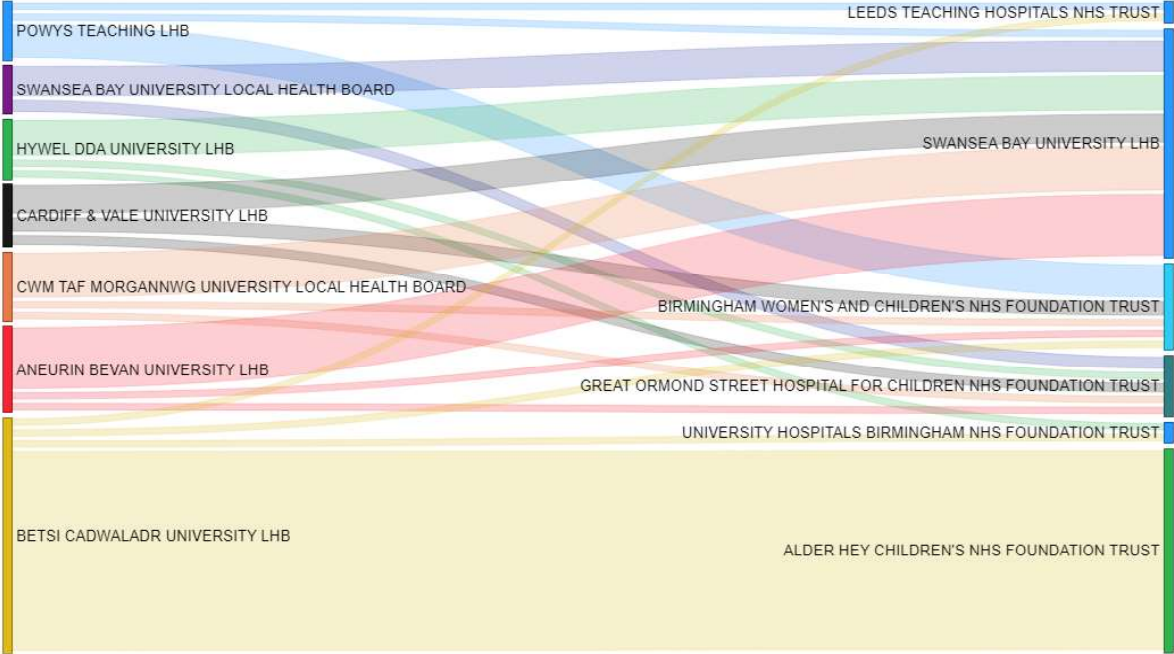
Neonatal and Mental Health services are excluded from this strategy as there are two additional strategic pieces being undertaken by WHSSC covering these areas, as noted within the WHSSC ICP 2021/24.

2.3 Current Configuration of Services & Associated Access

This section illustrates the flow from health board of residence to contracted provider for each of the specialised elements of the paediatric services WHSSC commissions. Health board of residence, based on GP postcode, is on the left and contracted provider is on the right (read left to right). The illustrations use information that WHSSC receives on commissioned activity and uses financial year 2019/20 information (pre-Covid-19). In some instances, links may be missing and this is mainly due to insufficient information from providers. The wider the connection, the higher the volume of patients accessing these services. There will be small numbers of flow to other providers that are off contract and these will be due a

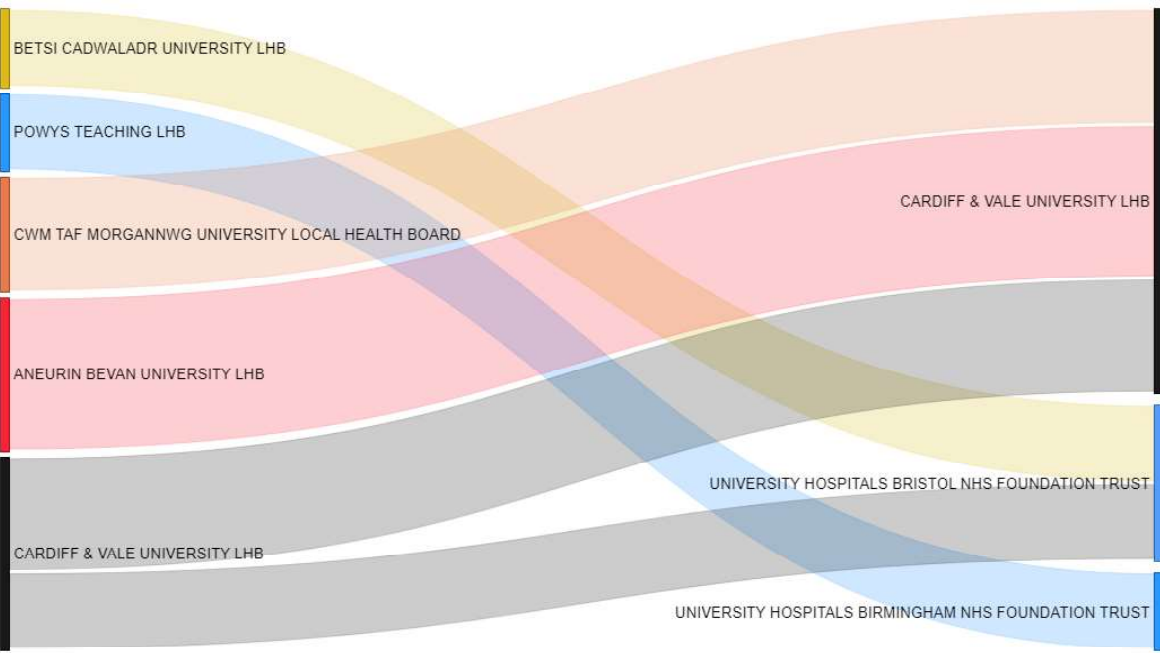
number of reasons such as an exceptional case considered by the Individual Patient Funding Request team or where a patient has become unwell whilst out of area.

2.3.1 Cleft Lip & Palate (CLP)



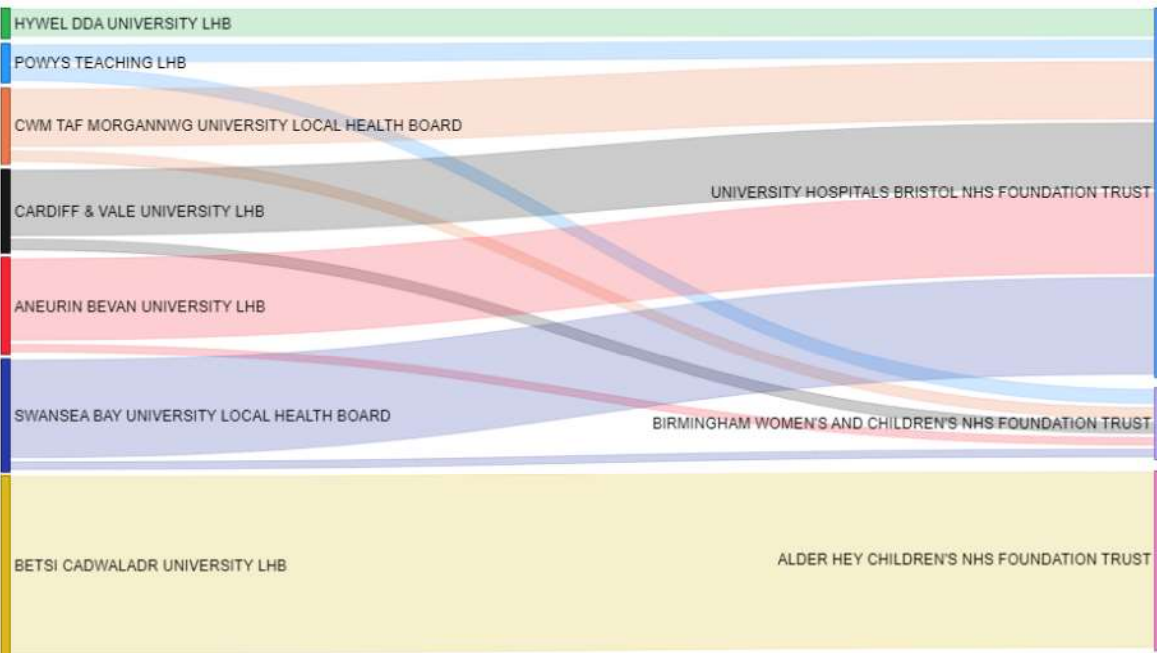
The commissioned pathway for children in north Wales requiring CLP treatment is to Alder Hey Children's Hospital, and for children in south Wales, it is to Swansea Bay. Powys patients, dependent on geographical location, flow to Birmingham Children's Hospital. Flow in the majority of cases aligns with the commissioned pathway. However there are small numbers flowing to alternative providers, such as Great Ormond Street Hospital, which are instances where patients with complex co-morbidities require treatment in a setting more appropriate for their needs.

2.3.2 Paediatric BAHA & Cochlear



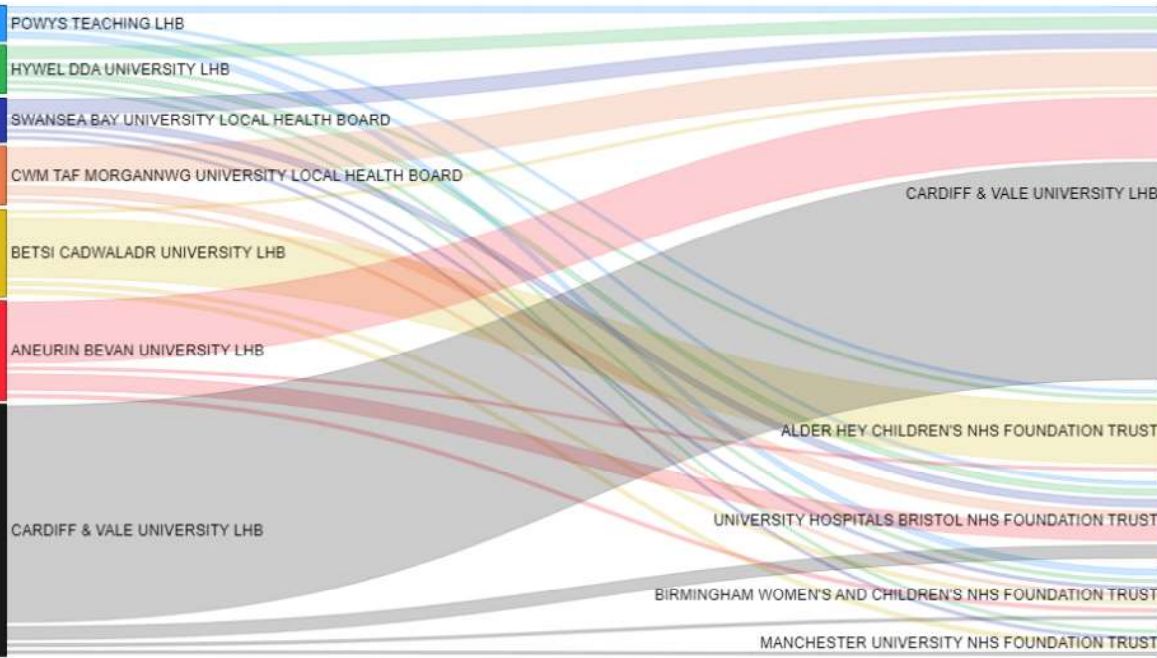
WHSSC commissions paediatric BAHA and cochlear services from three providers: Cardiff and Vale UHB and Swansea Bay UHB for patients in south Wales and south Powys and Central Manchester University Hospitals for patients in north Wales and north Powys. It appears from the chart that Hywel Dda and Swansea Bay residents have not accessed the service, this has been reviewed and it appears no data has been returned from SBUHB where these patients flow. The above illustrates that in 2019/20 there were also a number of patients treated at Bristol Royal Hospital for Children. This is in line with the commissioned pathway for patients with a cardiac condition requiring a BAHA or Cochlear implant.

2.3.3 Paediatric Cardiac Surgery



The commissioned pathway for children in north Wales requiring cardiac surgery is to Alder Hey Children's Hospital, and for children in south Wales it is to Bristol Royal Hospital for Children. The above illustrates that flows aligns with the commissioned pathway. As for all tertiary services, children with complex needs may need to be treated at highly specialised providers.

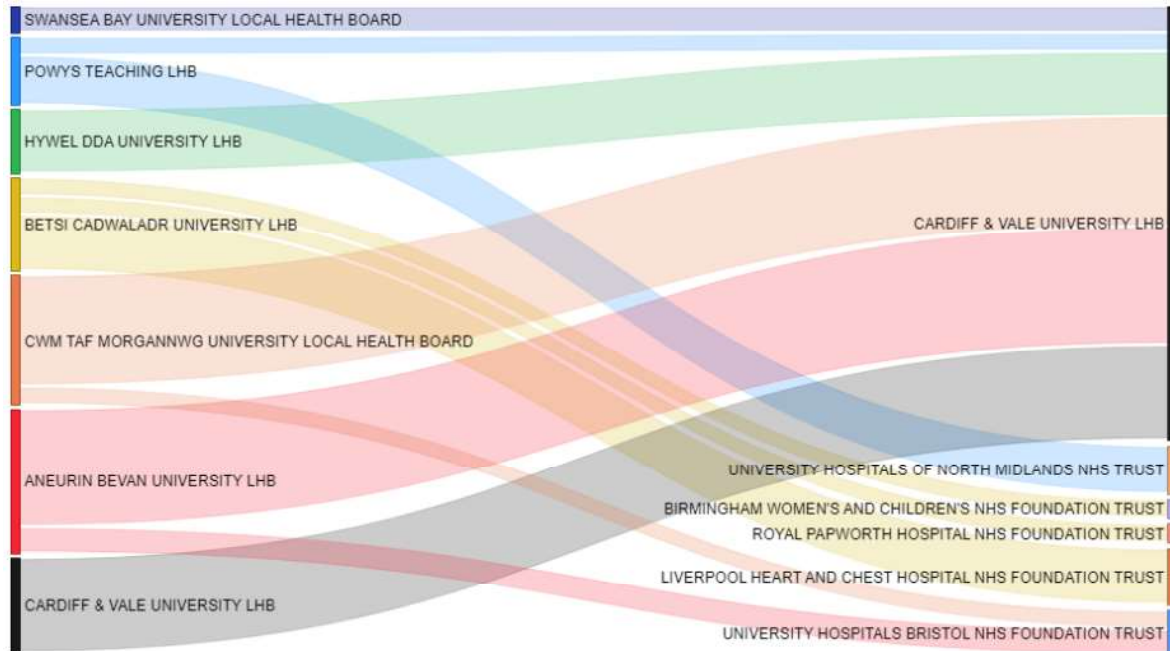
2.3.4 Paediatric Cardiology



The commissioned pathway for children in north Wales requiring paediatric cardiology services is to Alder Hey Children's Hospital, and for children in

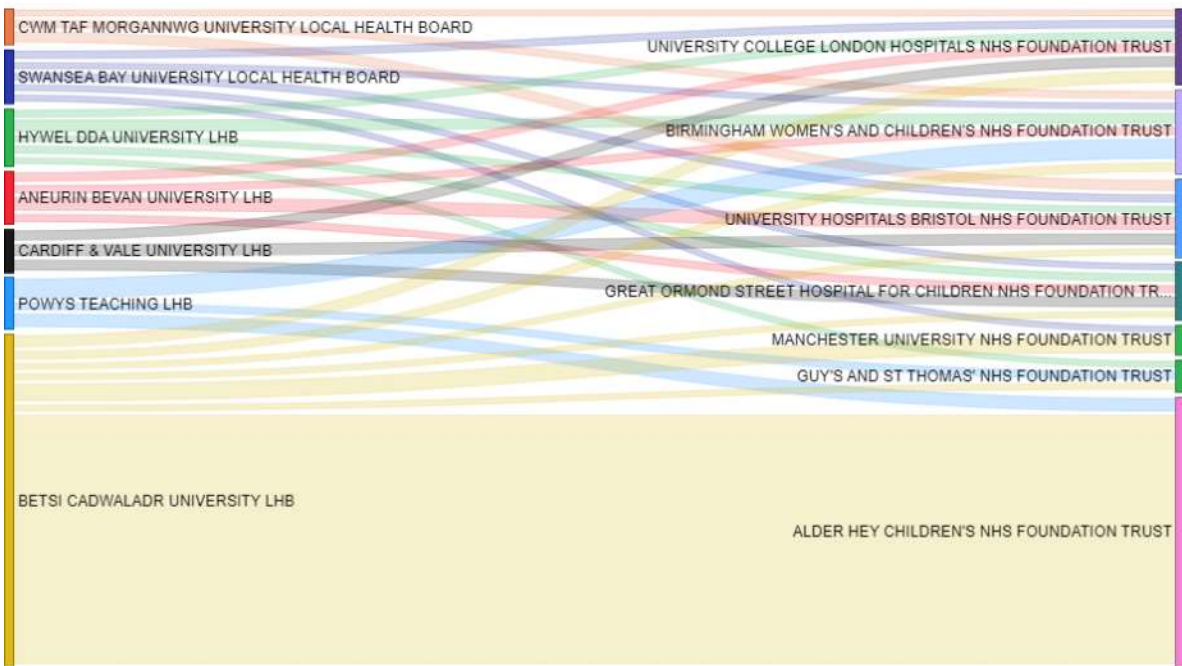
south Wales it is to Cardiff. [The flow for Powys patients is variable dependent on geographical location.](#) The above illustrates there are small numbers of patients that flow to alternative providers.

2.3.5 Paediatric Cystic Fibrosis



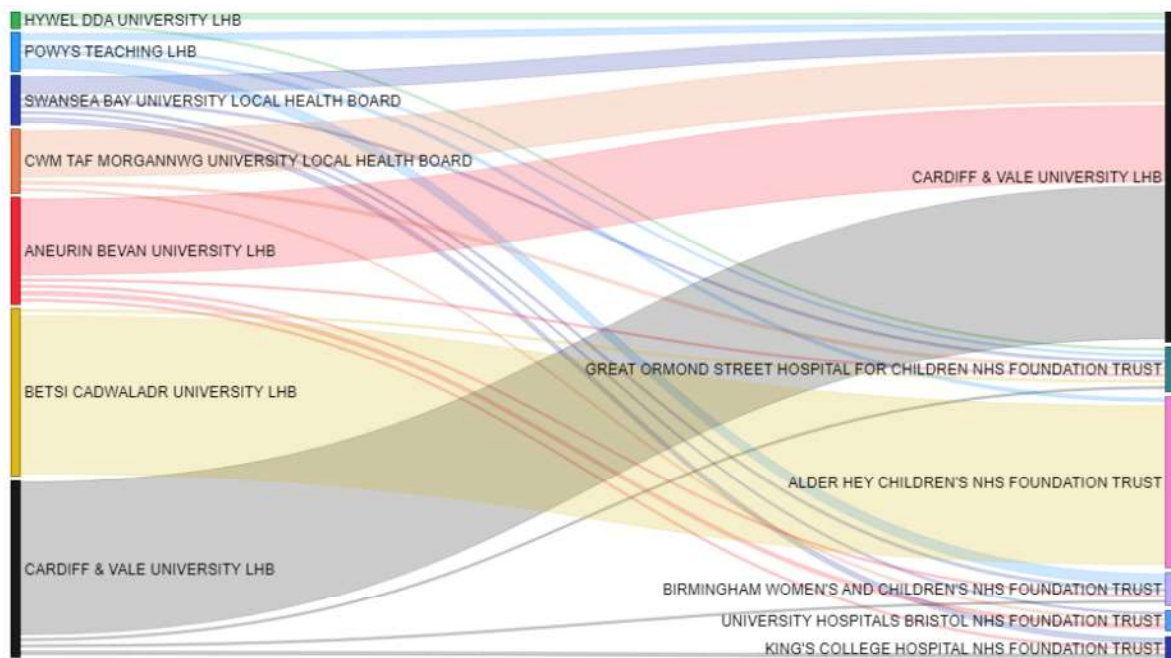
WHSSC commissions from ~~four~~three providers for paediatric cystic fibrosis services: Cardiff and Vale UHB for patients in south Wales; Birmingham Children's Hospital for patients in Powys ~~and~~; [Alder Hey Children's Hospital](#) [and](#) Liverpool Heart & Chest Hospital for patients in north Wales. The above illustrates that in 2019/20, the majority of patients followed the commissioned pathways, [as noted some expected links may be missing due to incomplete information from providers.](#)

2.3.6 Paediatric Endocrinology



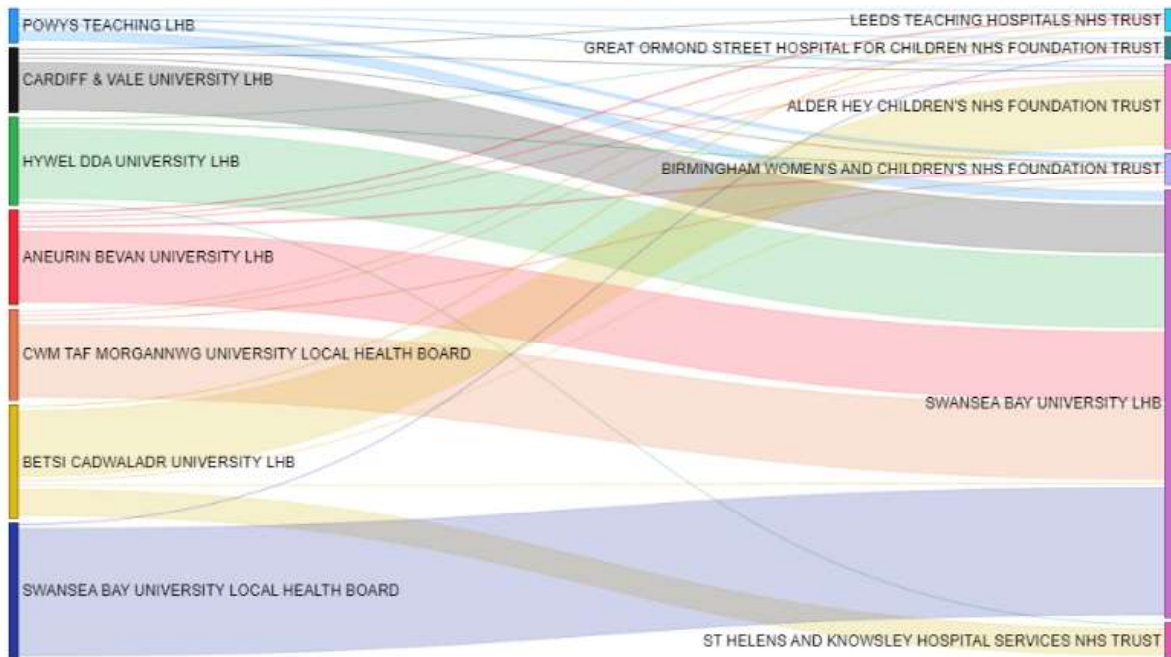
The commissioned pathway for children in north Wales requiring paediatric endocrinology services is to Alder Hey Children's Hospital, and for children in south Wales it is to Cardiff and Vale UHB. Dependent on geographical location, Powys patients flow to Birmingham Children's Hospital and Alder Hey Children's Hospital. The data in this chart demonstrates historic pathways from 2019/20, this was prior to the service being the commissioning responsibility of WHSSC. The service was subject to significant investment to support the appointment of the MDT. As the service in Cardiff and Vale UHB builds with funded appointments the flow for south Wales residents will be more consistent.

2.3.7 Paediatric Gastroenterology



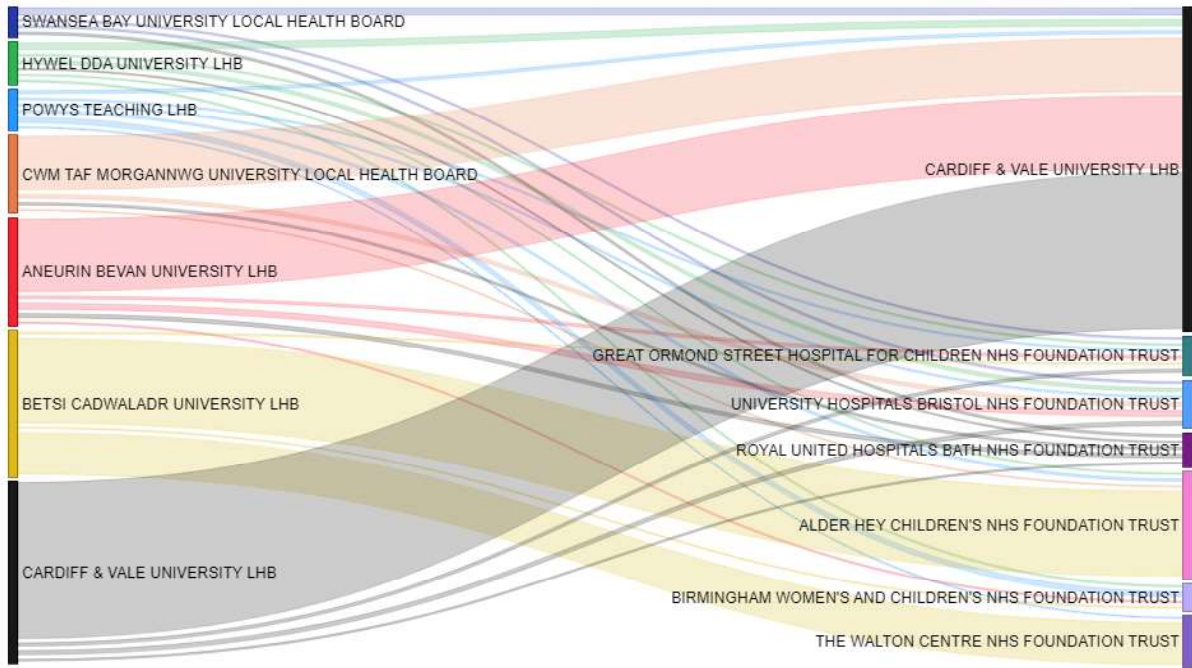
Commissioned pathways for children requiring paediatric gastroenterology services are to Cardiff and Vale UHB for those in south Wales and Powys, and to Alder Hey Children's Hospital for those in the north. Flow largely aligns with the commissioned pathways. For Paediatric Hepatology that is a highly specialised element of paediatric gastroenterology, south Wales and Powys patients flow to King's College Hospital London and Birmingham Children's Hospital, as per the diagram, and Alder Hey Children's Hospital for the north Wales population.

2.3.8 Paediatric Plastic Surgery



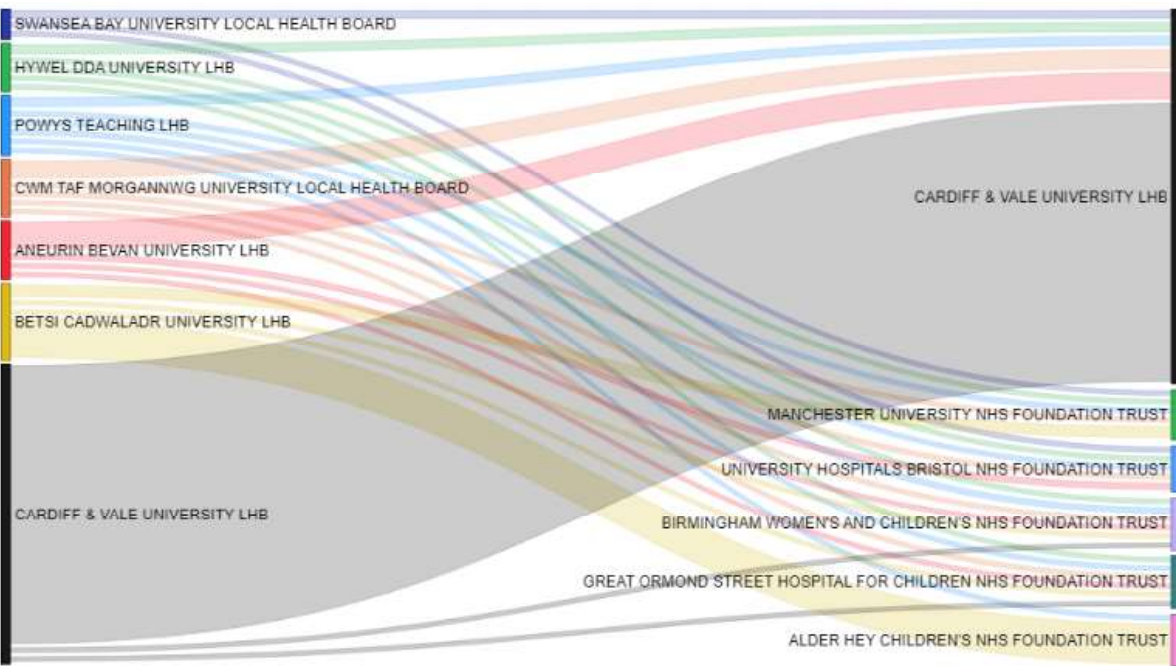
The commissioned pathway for children requiring paediatric plastic surgery is to Swansea Bay UHB for those in south Wales, to Birmingham Children's Hospital for those in Powys, and to Alder Hey Children's Hospital for those in the north. Flow aligns with the commissioned pathway, with a small number deviating. As previously noted for other services, this is broadly due to patients with complex needs and co-morbidities needing to access services from highly specialised centres.

2.3.9 Paediatric Neurology



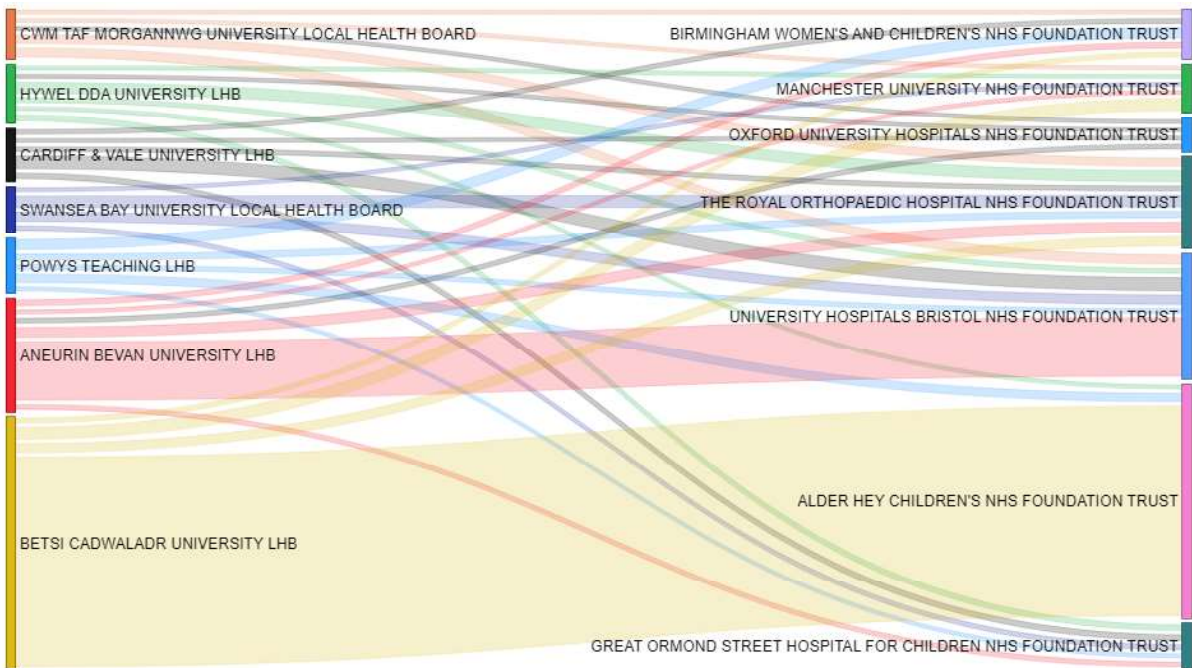
The commissioned pathways for children requiring paediatric neurology services are to Cardiff and Vale UHB for those in south Wales, the flow for Powys patients is variable dependent on geographical location and to Alder Hey Children's Hospital for those in the north. There are small pockets of flow to other providers across NHS England, these are for more complex elements of the pathway such as epilepsy surgery, as this procedure can only be carried out in 4 designated centres across NHS England.

2.3.10 Paediatric ENT



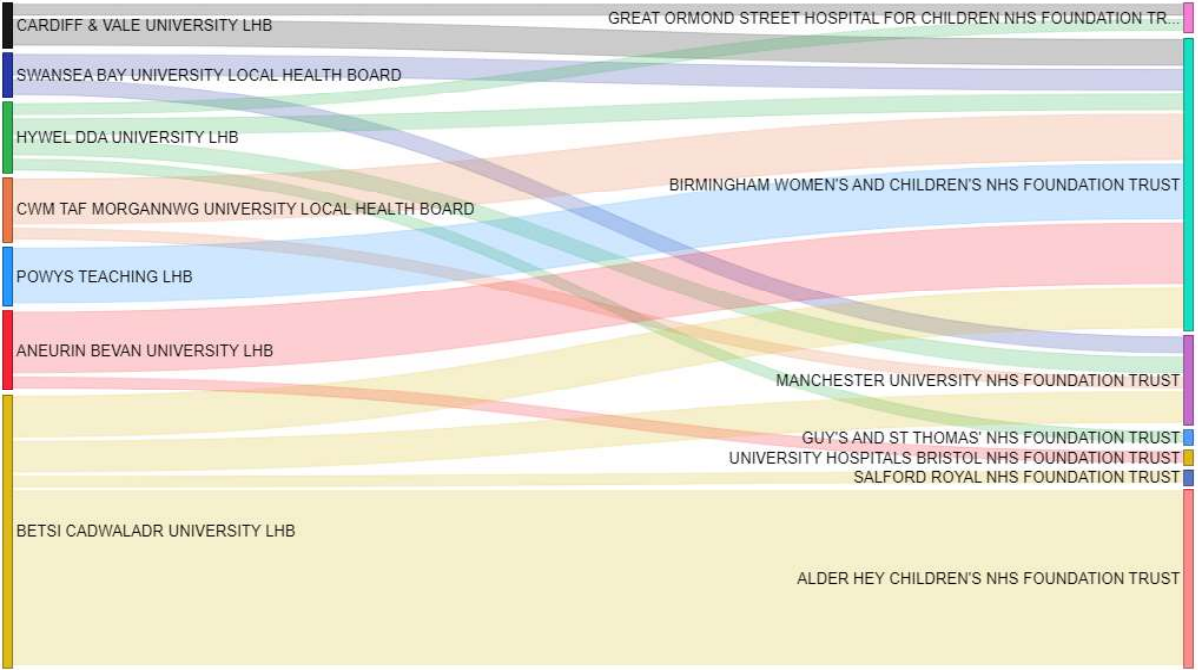
WHSSC commissions specialised paediatric ENT from Cardiff and Vale UHB for children from south Wales and Powys; and from Alder Hey Children's Hospital for children in the north. The above illustrates that a number of other providers were used in 2019/20. The work carried out by the surgical work-stream to define specialised paediatric ENT services should result in more consistent flow.

2.3.11 Paediatric Orthopaedics



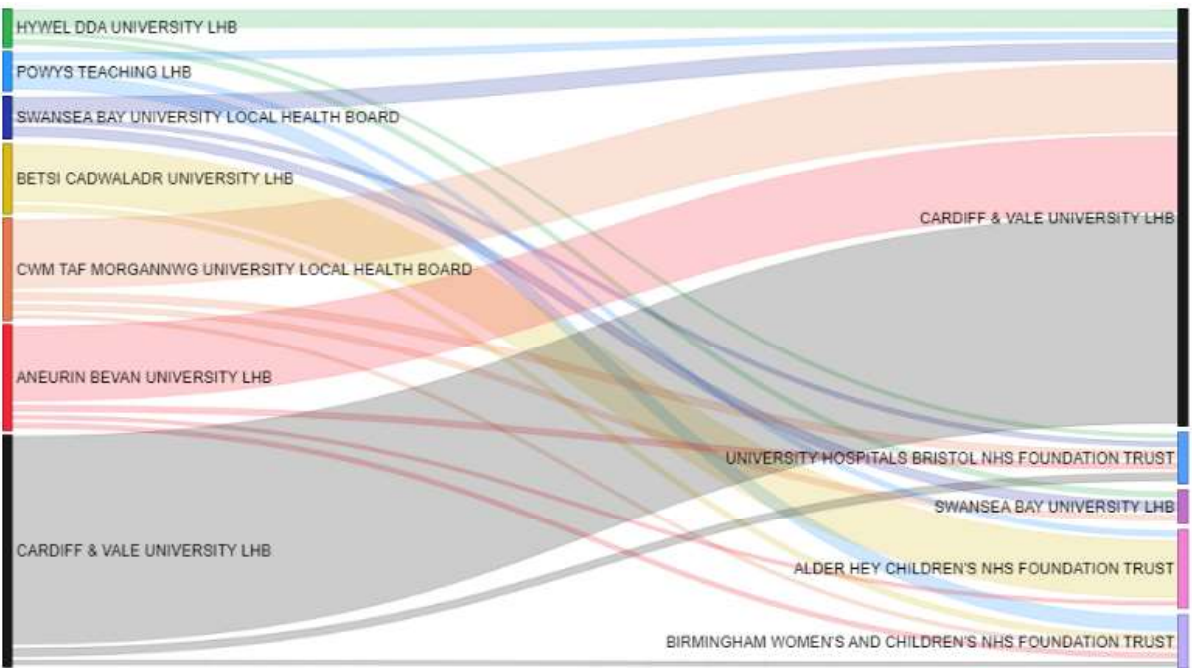
1 Specialised paediatric orthopaedic surgery is a newly commissioned service
2 by WHSSC from 2022/23. It is anticipated that the varied flow, particularly
3 illustrated by patients from south and mid Wales above, will become clearer
4 with the recently agreed service specifications.

6 **2.3.12 Paediatric Inherited Metabolic Disease (IMD)**



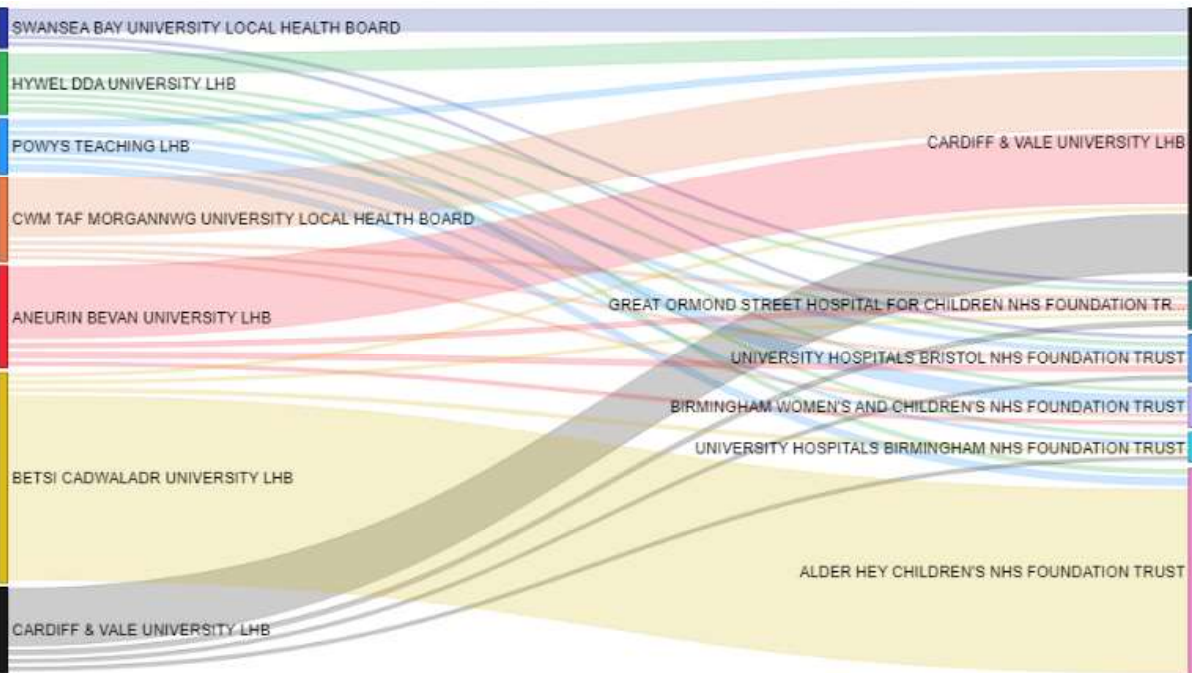
7
8
9 The main commissioned providers for Paediatric IMD are Birmingham
10 Children's Hospital for patients from south Wales and Powys; and Alder Hey
11 Children's Hospital for north Wales. There is flow to Manchester and Salford
12 which is expected for North Wales. Patients with the more rare conditions
13 requiring access to high cost Enzyme Replacement Therapy will be treated
14 through the respective IMD service dependent on geographical
15 location. ~~There is flow to Manchester and Salford which is expected for~~
16 ~~patients with the more rare conditions requiring access to high cost Enzyme~~
17 ~~Replacement Therapy.~~

2.3.13 Paediatric Nephrology



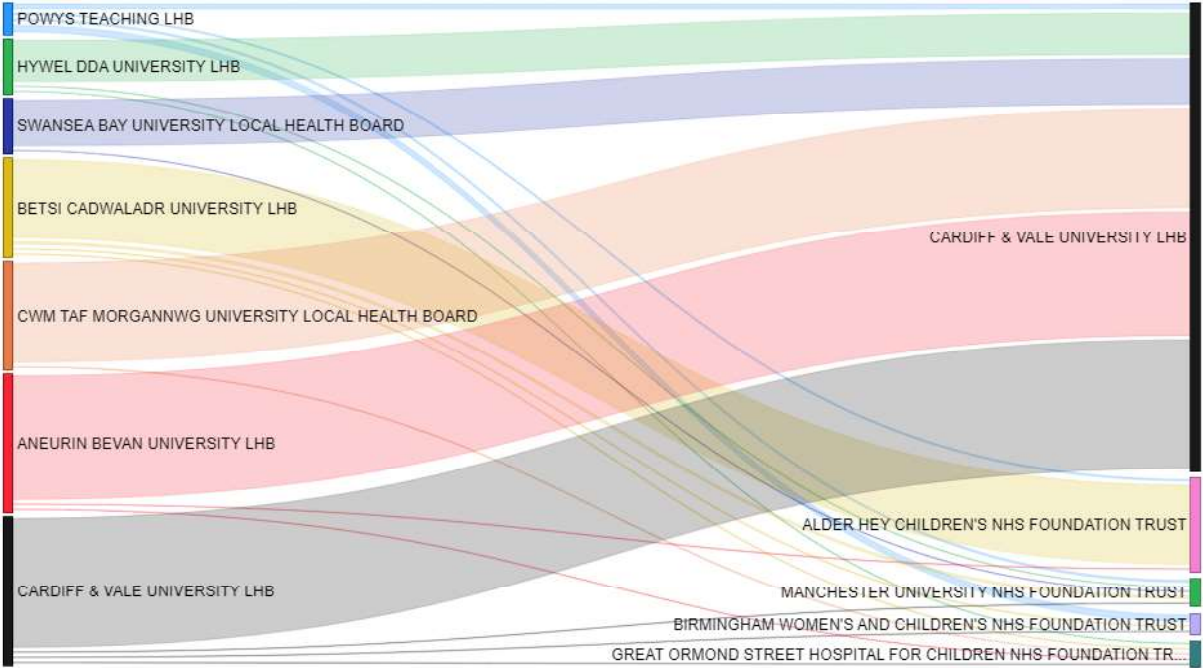
Paediatric nephrology services are commissioned by WHSSC from Alder Hey Children’s Hospital for children in the north of Wales, from Birmingham Children’s Hospital for patients living in Powys and from Cardiff and Vale UHB for patients in south Wales. These pathways are largely replicated by the activity flow for 2019/20 illustrated above.

2.3.14 Paediatric Neurosurgery



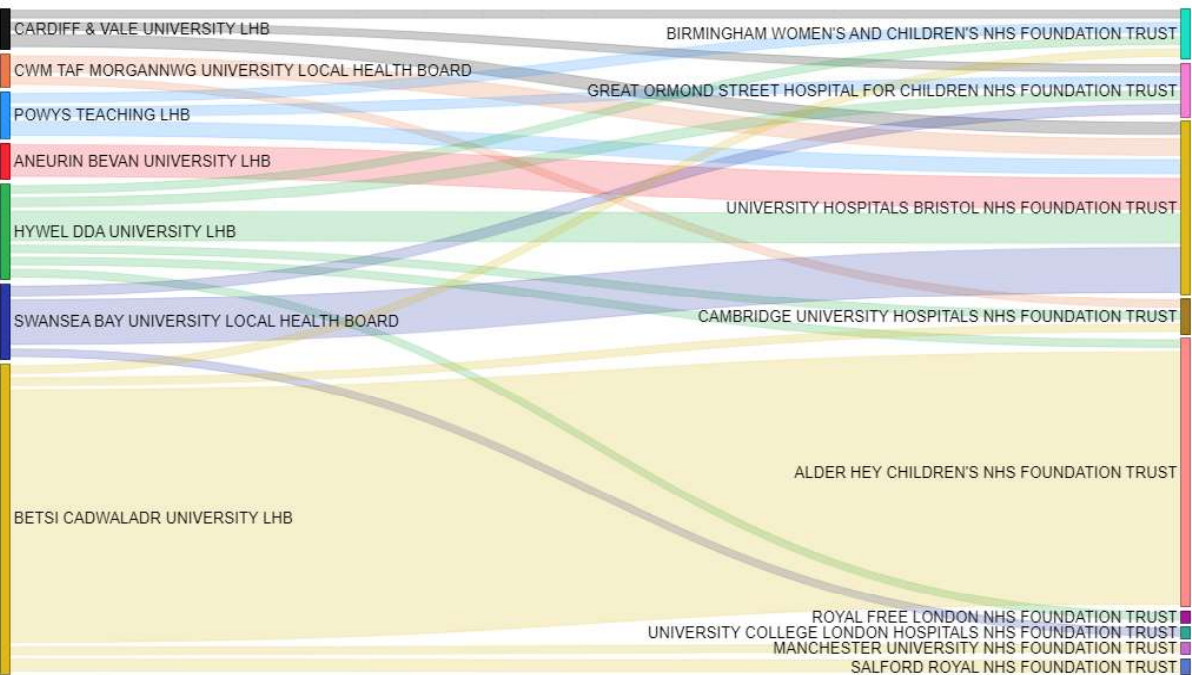
Commissioned pathways for children requiring paediatric neurosurgery are to Cardiff and Vale UHB for those in south Wales and Powys, and to Alder Hey Children's Hospital for those in the north. The flow diagram illustrates that there are small number flowing to alternative providers due to the requirement for highly specialised services such as craniofacial surgery.

2.3.15 Paediatric Oncology



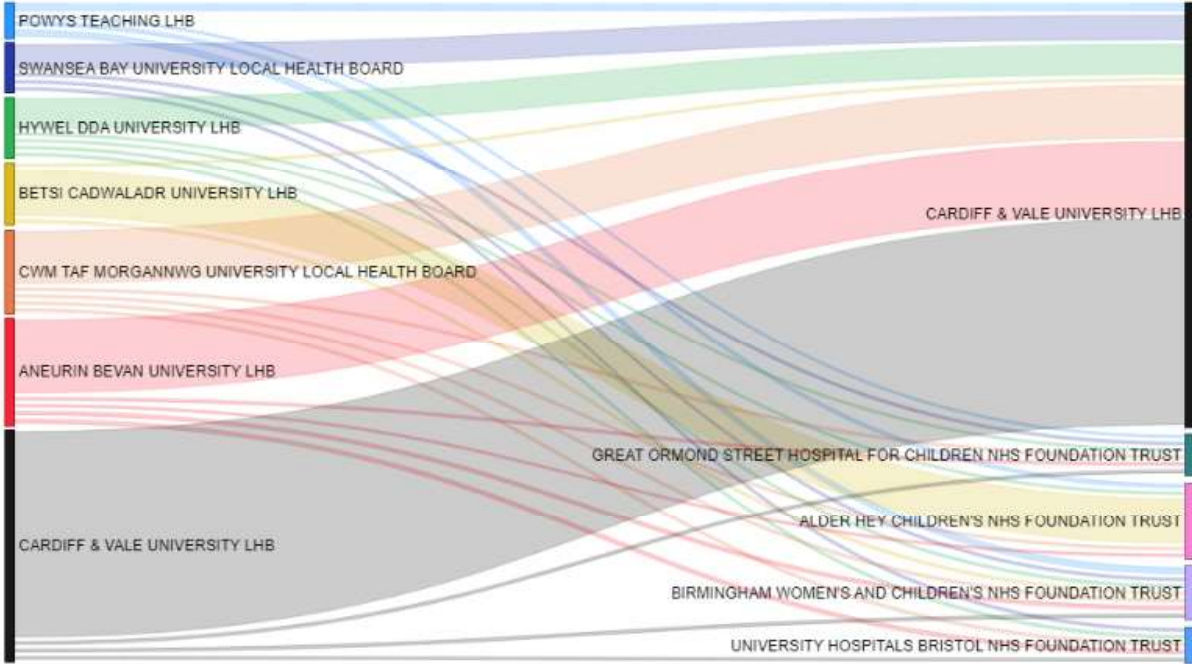
Services for children with cancer are commissioned by WHSSC from Alder Hey Children's Hospital for those in the north, from Birmingham Children's Hospital for those in Powys and from Cardiff and Vale UHB for those in the south. The diagram above, showing that some patients flow to other providers, illustrates activity for rarer forms of cancer.

2.3.16 Paediatric Rheumatology



The above flow diagram shows that patients from north Wales largely followed the commissioned pathway to Alder Hey Children's Hospital and Powys to Birmingham Children's Hospital. For patients in the rest of Wales, the picture is more mixed. A new service was developed and implemented in Cardiff and Vale UHB over two phases in 2019/20 and 2020/21. Due to the timing of recruitment, and therefore changes to patient flows, this is not demonstrated in the diagram. The investment will eventually demonstrate a far more consistent flow of patients to Cardiff and Vale UHB.

2.3.17 Paediatric Surgery



1 The main commissioned providers for Specialised Paediatric Surgery are
2 Alder Hey Children's Hospital for the north Wales population, Birmingham
3 Children's Hospital for the Powys population and Cardiff and Vale UHB for
4 the south and west Wales. There is expected flow to Great Ormond Street
5 and Bristol Royal Hospital for Children for complex patients and those with
6 cardiac conditions that require the expertise of these highly specialist
7 centres.

8 9 **2.3.18 Patient Flow Conclusions**

10 From the above, it is clear that the majority of patients are flowing to main
11 commissioned providers. However there are and always will be flow to
12 highly specialised providers due to the complex nature of their co-
13 morbidities. The principles of the strategy will impact on all commissioned
14 providers that treat the Welsh population to ensure the strategic objectives
15 are met.

16 17 **2.4 Current investment profile**

18 As of 2022/23, the contract value for paediatric specialised services for the
19 population of Wales is **£118million**, which is 16.4% of the WHSSC budget.
20 This is an increase of **£45million** since 2015/16 due to inflation,
21 investment through WHSSC ICP and growth. A full list of invested schemes
22 is available in **Table 3** (This does not include contractual rises).
23

1 **Table 3: Investment in Paediatric Services**

Service	Year of Investment	Investment aims	Update on implementation
Cardiff and Vale UHB			
Paediatric Surgery	2016/17	Following the removal of Deanery trainees, additional recurrent funding was provided to increase <u>Consultant</u> workforce and hold additional clinics <u>and theatre lists</u> .	Implemented in full.
Paediatric Oncology	2019/20	The service reported over-performance for a number of years and therefore it was agreed that there would be a contractual uplift.	Implemented in full.
Paediatric Neuro-rehabilitation	2017/18	To establish a paediatric neuro-rehab Multi-Disciplinary Team (MDT) to enhance the Paediatric Neurology service.	Implemented in full.
Paediatric Rheumatology	2019/20 and 2021/22	Funding across two phases to establish a Paediatric Rheumatology service supported by a full MDT.	Both phases implemented in full.

Service	Year of Investment	Investment aims	Update on implementation
Paediatric Gastroenterology	2021/22	Pan-south wales model with full MDT with 24 on-call provision, aligning with standards.	Implemented in part – funding release approved in December 2021, therefore posts are in recruitment phase.
Paediatric Endocrinology	2019/20	To stabilise a small service with full MDT to align with standards.	Implemented in part – only remaining post to recruit is Social Worker.
Paediatric Cardiology	2020/21	To deliver equitable outreach across the region that meets demand.	Implemented in full.
Paediatric Cystic Fibrosis	2021/22	Following approval of Kaftrio, investment in pharmacy to support roll-out and ongoing care of patients.	Implemented in full.
Paediatric Intensive Care	2019/20	Recurrent funding to increase bed capacity to 7 and increase nursing infrastructure to align with standards.	Implemented in full.
BAHA and Cochlear	2017/18	Recurrent investment to align with providers across the UK following a benchmarking exercise.	Implemented in full.

Service	Year of Investment	Investment aims	Update on implementation
Children's Hospital for Wales	2015/16	Recurrent funding as part of the phase 2 of the Children's Hospital.	Implemented in full.
Paediatric Inherited Metabolic Disease	2021/22	Due to a joint model with NHS England, investment in nursing and dietetic infrastructure at C&VUHB.	Implemented in full.
Paediatric Neurology	2021/22	Pan-south Wales model with full MDT with 24 on-call provision, aligning with standards.	Implemented in part – a number of posts remain unfilled due to national shortages of Paediatric Neurologists.
Paediatric Clinical Immunology	2021/22	Increased capacity to manage growth.	Implemented in part Not implemented – funding release approved in March 2022.
Paediatric Radiology	2021/22	To support 24-hour paediatric radiology services <u>in south Wales</u> , with outreach support for local units.	Not implemented – funding release approved in December 2021, therefore posts are in recruitment phase.
Swansea Bay UHB			

Service	Year of Investment	Investment aims	Update on implementation
Cleft Lip and Palate (MDT)	2019/20	Funding to strengthen the MDT and ensure sustainability within the core infrastructure.	Implemented in part – recruitment to Consultant sessions remains outstanding due to UK wide shortage.
Cleft Lip and Palate (RTT)	2019/20	Following a historic backlog of adult cases, non-recurrent funding was approved to provide additional surgical sessions.	Implemented in part – the pandemic impeded delivery. Work is ongoing to address remaining backlog.
Bristol Royal Hospital for Children			
PICU retrieval	2015/16	The historic 7 th bed in C&VUHB was decommissioned in 2015/16 to fund the service.	Fully implemented

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CHAPTER 3

3.0 PRESENTATION OF FINDINGS FROM THE PROGRAMME STRUCTURE

In order to inform this strategy, intelligence and data was gathered through the programme structure in order to develop priority areas for inclusion. The following offers a summary of the issues that emerged through this process. They are presented as they emerged from the structure, however are drawn together in the following chapter against the strategic objectives:

3.1 Summary of issues from the Collective Commissioning Sub-group

Since 2019/20, three paediatric services, previously the commissioning responsibility of Health Boards, have been delegated to WHSSC for commissioning; Paediatric Endocrinology, Paediatric Radiology and more recently Specialised Paediatric Orthopaedic Surgery. A review of services was undertaken in order to bring clarity to the range of specialised services that WHSSC commissions. The list was derived from a number of sources, including:

- Review of the [NHS England Manual for Prescribed Specialised Services](#)
- Requests from the Service Modelling Group
- Suggestions made by members of the project structure

The services considered were:

High Dependency Unit capacity for specialised services	Ophthalmology
Autism	ENT surgery
Chronic Pain	Ehlers Danlos pathway
Specialised Respiratory	Chronic fatigue
Infectious Diseases	Paediatric Radiology

Of these, the following are already WHSSC commissioned services:

- **Ehlers Danlos** is already commissioned by WHSSC and is included in the service specification for Paediatric Rheumatology
- **Paediatric Radiology** received investment in 2021/22
- **Specialised Paediatric ENT** - This service is currently delegated for commissioning responsibility through WHSSC and the list of inclusions has been considered through the Paediatric, Surgery work-stream

1 It is proposed that the following service areas are included within the
2 WHSSC portfolio and will require approval and support by Joint Committee
3 to formally delegate:

4
5 **Specialised Paediatric Respiratory** - Whilst WHSSC already
6 commissions home ventilation and cystic fibrosis services, there are other
7 aspects of respiratory services which could be commissioned by WHSSC as
8 a specialised service as it is a strong strategic fit as WHSSC already has
9 commissioning responsibility for Cystic Fibrosis and the Paediatric Sleep
10 service. The tertiary elements would, however, need to be tightly defined
11 so as to avoid care which should be provided at a secondary level being
12 provided at a tertiary centre. NHS England already commission specialised
13 respiratory services.

14
15 **Specialised Services for Paediatric Infectious Diseases** - WHSSC
16 Joint Committee agreed in September 2022, that Specialised Services for
17 Paediatric Infectious Diseases should be a service commissioned by WHSSC
18 and worked up during 2022/23. In NHS England, the service is
19 commissioned as a specialised service alongside Paediatric Clinical
20 Immunology which is a specialised service already commissioned by
21 WHSSC and therefore would benefit from synergies and cohesion if
22 commissioned.

23
24 **Specialised Paediatric High Dependency Unit (HDU)** - The sub-group
25 made the distinction between HDU which is required as a step-down from
26 paediatric intensive care (PIC) and HDU within secondary care. This will
27 allow for the episode of tertiary care to be formally commissioned. The
28 former was considered and agreed that specialised HDU capacity should be
29 recommended for commissioning by WHSSC.

30
31 **Specialised Services for Paediatric Chronic Pain** - During the recent
32 Paediatric Rheumatology Service Specification consultation, there were a
33 number of comments relating to establishing a Chronic Pain Service. It is
34 proposed that further work is done to develop clear acceptance criteria to
35 underpin the service and recommended formal commissioning by WHSSC.

36
37 **Specialised Paediatric Ophthalmology** - The commissioning criteria for
38 specialised paediatric ophthalmology has been considered through the
39 paediatric surgery work-stream.

40
41 The sub-group concluded that both autism and chronic fatigue services
42 should remain within the remit of Health Board commissioning, pending the
43 development of clear local pathways of care for these patients, where the
44 criteria for a 'specialised' service may become better defined. Should these

develop in the future, then these services can be considered for commissioning by WHSSC through the standard processes.

3.2 Summary of issues from the Workforce Work-stream

Over the past 5 years, the WHSSC Women and Children's commissioning team has worked with colleagues across Wales to identify and address deficiencies in the provision of specialised services for Children and Young people. A key theme throughout has been workforce risks across a number of different domains. Notably there have been risks due to an ageing workforce with little to no succession planning, changes in training that impact on 'like for like' replacements and significant gaps and shortages in specific professional areas. Therefore, when developing the strategy, it was decided a workforce sub-group was essential in attempting to resolve and mitigate a number of these risks in a more strategic and sustainable way.

Based on the overarching vision of WHSSC, the strategy needs to support the development of a workforce that has the capabilities for, and is supported in, delivering safe, effective and sustainable specialised services that meets the needs of the children of Wales.

To inform the strategy, a series of workshops was held in order to engage with a wide range of stakeholders from the breadth of professional groups that contribute to caring for children within specialised services, from both Welsh and English provider organisations and colleagues from HEIW. Documents including the NHS Wales "[A Healthier Wales: Our Workforce Strategy for Health and Social Care](#)", the King's Fund document '[Closing the gap](#)' and a Harvard Business Review paper on '[Creating the Best Workplace on Earth](#)' were circulated and considered as part of the process. Mentimeter exercises were also used to engage and provide anonymous insights on positive aspects of current work and workplace and where positive changes could be made.

Stakeholders were asked:

- How can we, through the commissioning of specialised services, support specialised children's services being the 'employer of choice' for health care workers?
- How can we, through the commissioning of specialised services support the creation of the conditions where staff are effective in delivering the required care?

Themes emerged which can be subdivided into those which the commissioning strategy can seek to address and those which are beyond the remit of WHSSC and therefore the strategy can support in principle but are for provider organisations and/or HEIW to take forward:

Contracting barriers - A number of consistent themes developed through discussions, in the main articulating some of the barriers with existing commissioning and the unintended consequences this has on the provider's ability to recruit and staff, in particular part-time speciality specific posts that then become unattractive to fill and unsustainable. Providers noted it was challenging through Health Board processes and timings of investment to merge posts from different WHSSC contract lines.

Specialty posts - A range of complexities and barriers with current commissioning of posts within a specialty area were raised, which posed restrictions with cross-cover and the attractiveness of posts due to limited exposure to specific conditions. A number of mitigations were in train in NHS England to address these issues and through discussions with individual providers throughout the development of the strategy, we have learnt of pockets of good practice and innovative models for staffing structures.

Development of services - A further recognised theme was the lack of input referring health boards had in the development of services within a tertiary setting. Although the WHSSC structures have representatives from all providers across Wales, this is at the approval stages. Further engagement and involvement of staff from all Health Boards in service design from the outset would ensure more joined up pathways as an understanding of provision locally would be understood.

Specialised paediatric services are part of the wider system of healthcare for children, including hospital based and community services and spanning primary, secondary and tertiary care. In order for the whole system to work effectively in delivering high quality care, the right number of staff with the right skills are needed across the entire system. Consequently there needs to be a children's services workforce strategy for Wales encompassing all these elements.

As [A Healthier Wales : Our Workforce Strategy for Health and Social Care](#) offers a helpful framework, the 7 core themes of this are utilised in the '**Where we want to be**' section of this strategy in order to present key priorities for consideration when commissioning Specialised Paediatric Services.

3.3 Summary of issues from the Quality and Governance Sub-Group

The quality of care and experience that patients and their families receive, is central to the commissioning of specialised services. Over recent years,

1 in particular with investment and development of newly commissioned
2 services, it has become clear that despite numerous documents and
3 initiatives in place from across NHS Wales and NHS England, the reporting
4 and measurement of service quality has been variable as has the
5 interaction and escalation to and with the tertiary commissioner. There
6 have been a number of contributing factors to the variability, in particular
7 the timing of service specification development, the timing of new evidence
8 and quality measurement processes along with the publication of new
9 national guidance.

10
11 **Appendix E** provides a summary of the each of the supporting information
12 systems.

13
14 The strategy will be required to support the consistent reporting in line with
15 the [NHS Wales Quality and Safety Framework](#) (Welsh Government 2021)
16 **Assurance**, using the Institute of Medicine (1999) six domains of quality to
17 support a systematic approach:



20
21 **Safe:** Avoiding harm to patients from the care that is intended to help
22 them.

23 **Timely:** Reducing waits and sometimes harmful delays for both those who
24 receive and those who give care.

Effective: Providing services based on scientific knowledge to all who could benefit and refraining from providing services to those not likely to benefit (avoiding underuse and misuse, respectively).

Efficient: Avoiding waste, including waste of equipment, supplies, ideas, and energy.

Equitable: Providing care that does not vary in quality because of personal characteristics such as gender, ethnicity, geographic location, and socioeconomic status.

Patient-centred: Providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions.

These characteristics of quality align with NHS Wales' prudent health and care principles⁴. **Figure 12** summaries the 4 principles of prudent healthcare.

Figure 12 – Prudent Healthcare



Due to the breadth of specialised paediatric services, a 'one size fits all' approach will not be appropriate as specialties have nationally validated quality and outcome indicators and submit data to national audits for benchmarking.

During the implementation of the strategy, agreement with each specialty will be sought on the best evidence of the quality of that service under each domain. The range of data available will provide evidence in relation to:

- outcomes
- service specific quality indicators
- process data
- patient experience
- impact data
- workforce

⁴ [Prudent Healthcare: Securing Health and Well-being for Future Generations](#)

1
2 The above are the standard principles to meet the strategic objectives and
3 provide the required assurance, however it is important to note that if there
4 are areas of concern or where services are falling short of the expected
5 standard of quality existing WHSSC process such as the escalation process
6 will be initiated.

7
8 To inform the strategy, the Quality and Governance sub-group identified a
9 number of themes that the commissioning strategy will seek to address.
10 Commissioning health boards do not currently feel that they receive formal
11 assurance on the quality of specialised services, in particular at service level
12 compared with others and, if required, improvement work is making a
13 difference.

14
15 Stakeholders acknowledged that the breadth of commissioned children's
16 specialised services along with the number of providers from NHS Wales
17 and NHS England presents a challenge for the WHSSC team from a quality
18 assurance perspective, with the need for a systematic approach to
19 receiving, reviewing and sharing information in order to provide overall
20 assurance that the system is working effectively to deliver the outcomes
21 that we need for the children of Wales.

22 23 **3.4 Summary of issues from the North Wales Sub-Group**

24 In 2018 the Women and Children's commissioning team was asked by the
25 BCUHB commissioning team and the WHSSC finance team to look at
26 whether there were opportunities for efficiencies in the way paediatric
27 specialised services are delivered for the North Wales population. This work
28 commenced in 2019, however due to Covid-19 the work paused. As the
29 issues remained relevant it was agreed that a North Wales sub-group would
30 be best placed to make recommendations on a strategic model for access
31 to tertiary services for the population of North Wales.

32
33 As the pathway to Alder Hey Children's Hospital is well established, with
34 expertise and critical mass to sustainably deliver safe and efficient tertiary
35 services, the remit of the group was to consider the outreach element of
36 the pathway. Throughout engagement with the strategy sub-group,
37 together with historical knowledge and meetings with the north wales
38 teams, a number of themes were identified.

39
40 The themes identified are consistent with those that have been raised and
41 considered by all of the sub-groups within the strategy structure. Therefore
42 the strategy will ensure that the implementation plan is equitable in its
43 expectations and outcomes for all providers of tertiary services.

3.5 Summary Of Issues From The Surgery In Children Work-Stream

For all surgical specialities over the past 20 years, there has been a gradual decline in the number of children who have received their surgery in a District General Hospital (DGH), whilst the numbers of children receiving surgery in specialised centres has risen by a corresponding level. In the recent NHS England review⁵, this was most marked for children aged 0-4 years of age for routine surgical procedures. Specifically, for General Paediatric Surgery (GPS) (e.g. inguinal hernia, undescended testes, acute appendicitis) analysis from NHS England (2013-17) demonstrates a continuing steady year on year growth in GPS activity performed in specialist centres of around 6%. In some areas of the country, this development has led to increased waiting times for elective procedures in specialised centres and limited children's access to urgent or emergency routine surgical procedures out of hours, outside of specialised centres. It is likely that the pandemic will have exacerbated this situation significantly.

The aim of this work-stream was to improve sustainability of services and equity of access across Wales and to ensure a model that supports the right pathways for children and their families, ensuring that all patients can access the right care, in the right place, at the right time.

With the timing of this work in relation to the pandemic, it was agreed that there were opportunities for synergy:

- Recovery from the impact of Covid on services
- Creating a sustainable model for the future delivery of surgery in childhood

The number of referrals to specialised centres for surgery in childhood has been on the increase for a number of years, and it has been difficult to define which conditions require 'specialised' commissioning. To inform the strategy, research into a number of existing documents and reviews was undertaken, and discussed with surgeons from across a broad spectrum of services. There are 4 key documents of relevance which highlight the issues and detail the advice and recommendations of professional bodies for the future configuration of surgical services for children:

- [Working together to improve the local delivery of the general surgery of Childhood \(Royal College of Surgeons 2018\)](#)
- [Safe Delivery of Paediatric ENT Surgery in the UK: A National Strategy - A Report of a Combined Working Party of the British Association for Paediatric Otolaryngology \(BAPO\), ENT UK, The Royal](#)

⁵ [Paediatric critical care and surgery in children review: Summary report November 2019](#)

[College of Anaesthetists \(RCoA\) and the Association of Paediatric Anaesthetists of Great Britain and Ireland \(APAGBI\) \(2019\)](#)

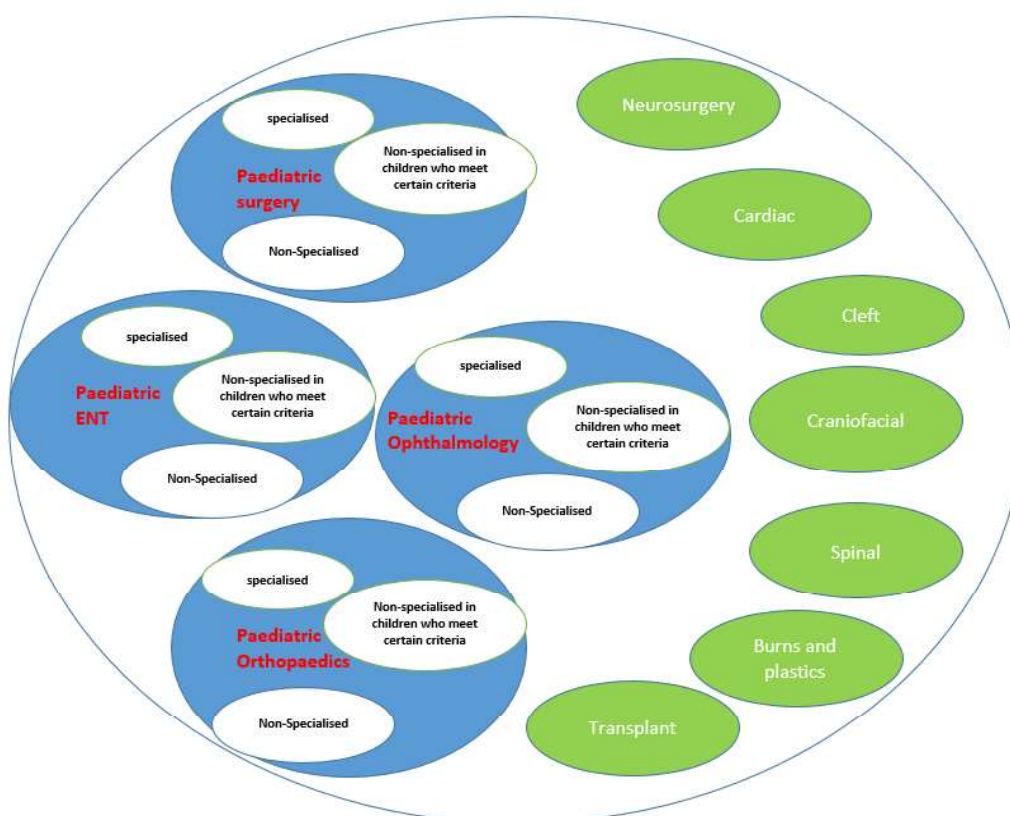
- [Guidelines for the provision of Paediatric Anaesthesia Services \(Royal College of Anaesthetists 2022\)](#)
- [The GIRFT report on Paediatric Surgery and Urology \(2021\)](#)

The GIRFT review of Paediatric Orthopaedics was in progress at the time this work was undertaken and has recently been published and the GIRFT reports on ENT surgery and Spinal Surgery have recommendations of relevance to children.

From a specialised services commissioning perspective, children's surgical services are viewed as being in one of 2 groups:

- Surgical services which are purely specialised (green on the diagram below)
- Surgical services which have specialised elements which sit in the context of a wider system of surgical care (blue on the diagram below) with elements delivered in every LHB

The system of surgery in children:



Feedback on the current situation, included the following key points:

- Variation across Wales in provision of required support and infrastructure and variability in cases that were assessed as being suitable for surgery locally, even within the same Health Board.
- Particular challenges were raised in relation to access to radiology and anaesthesia, especially out of hours.
- Change in workforce where some clinicians have undertaken different training routes meaning they are not able to operate on some patients, resulting in difficulty in accessing services locally where routine surgery is needed, or long waiting times at specialised centres.
- These pathway changes, which have evolved organically, have been further affected by changes in workforce training and surgical experience for both surgeons and anaesthetists, meaning that services have stopped being provided from some centres, increasing the demand for routine activity in specialised centres.
- There is difficulty for commissioners, in accessing data on accurate levels of activity and costs of the different types of surgery (split between specialised and routine) due to how the data is currently coded.

Principles developed through the work to develop this strategy are:

- Non-specialised surgery will be provided in all levels of hospital, with local pathways being agreed through a networked approach for the type of surgery provided in each hospital linked to the skills and competency of staff, type of patient and clinical indication.
- Specialised surgery will be provided in the specialised tertiary hospitals/units.
- Clearly defined anaesthetic criteria that will indicate the need for children requiring non-specialised procedures to be operated on at the tertiary centre.

While WHSSC would lead on the development of service specifications for the tertiary services, including the non-specialised work in children that meet certain criteria, a wider discussion would need to take place within NHS Wales with regard to how work will be taken forward to develop service specifications for surgery in children in UHBs, which will all have a common infrastructure and supporting structure requirement. It is acknowledged that the service specifications for specialised surgical services and general surgical services (commissioned by Health Boards) need to ensure a seamless service for our paediatric patient population.

1
2 A discussion is also required within NHS Wales regarding the opportunities
3 a Network for Surgery in Children would provide.
4

5 **Surgical services which are purely specialised**

6 As per the diagram above there are a number of commissioned specialised
7 surgical services that are not part of a wider system of surgical care.
8

9 **Commissioned from NHS England**

10 **Cardiac surgery** - The amount of surgery for Congenital Heart Disease
11 (CHD) has been slowly declining over the past 7 to 8 years. This is partly a
12 reflection of falling birth rates as demonstrated in **Figure 8** in Chapter 2.
13 The service specification for CHD requires surgical centres to have a team
14 of four surgeons each undertaking at least 125 operations per year due to
15 the declining numbers, this is now unattainable for many centres. To
16 mitigate the risk and manage numbers in the future, discussions with NHS
17 England have noted that when service specifications are due for review, the
18 focus will be on patient outcomes not prescriptive inputs.
19

20 **Craniofacial and Transplant-** Discussions with NHS England have
21 concluded that there are no anticipated strategic developments in NHSE
22 over the next 5 years.
23

24 **Commissioned within NHS Wales**

25 **Paediatric Neurosurgery, Cleft surgery, Spinal surgery and Burns**
26 **and Plastic surgery** - These services are commissioned from providers in
27 NHS Wales, a full review of pathways and Multi-disciplinary Teams in order
28 to enhance provision will be undertaken, in line with the strategic
29 objectives.
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CHAPTER 4

4.0 WHERE DO WE WANT TO BE?

4.1 Vision for the future

The overarching vision for this strategy is: "...to develop a 5 year commissioning strategy for the provision of high quality, sustainable and equitable specialised paediatric services for the children of Wales." This vision will improve outcomes for children accessing specialised services to ensure a more resilient population by contributing to improvements such as school attendance and attainment. The vision has been developed in partnership and been driven through the principles outlined in the following section.

4.2 Principles

- High quality specialised care provided to patients in the correct place and at the right time in the least restrictive environment appropriate for their treatment.
- Whole pathway approach with the development of nationally agreed seamless and complete clinical pathways for children and young people.
- Providing more care closer to home wherever safe and practicable to do so; primarily in the Welsh NHS but where necessary, and appropriate, from NHS England.
- Equitable access to outreach clinics and provision for education and training of staff both locally and specialist.
- Developing commissioning models which add value and strengthen the whole pathway approach to service delivery supporting the transforming health care agenda within Wales.
- Addresses the challenge of improving outcomes and transitions between different parts of the pathway and commissioning organisational boundaries.
- To prioritise investment in areas with demand and capacity constraints and areas with extended waiting times and/or gaps in service.
- Consider the horizontal and vertical delivery of specialised services on order to allow professional groups to deliver what patients need 7 days a week.

4.3 Strategic Objectives

As a result of conversations to inform this strategy, a number of strategic objectives have been developed against which key actions are developed to take the strategy forward. These objectives are outlined below:

Strategic Objective 1

There are clear access criteria and routes into and out of tertiary services for Children and their families, with increased knowledge of the remit of specialised services provision and how they fit within the whole pathway of care.

The implementation of the strategy will see the inclusion of a number of new services to be commissioned over the course of the 5 year implementation phase. Clear access criteria will be developed to ensure the tertiary elements are clearly defined.

Strategic Objective 2

Children receive high quality, equitable and patient tailored care in the most appropriate environment, whether that be in-reach or outreach, with clinical teams supporting the use of advanced digital technologies and regional education and training.

When developing services in the future a standard requirement set by WHSSC will require tertiary providers to work with secondary care providers to ensure consideration is given to local provision across the entire pathway. During the review of existing services and development of new services, due regard to the commissioning of outreach and in-reach provision will be a requirement. This will allow:

- local skills and expertise to be fully utilised;
- reduced creep from secondary care to tertiary care
- any gaps at secondary care are addressed to support resident Health Boards in developing local services or commissioning for their local population
- consideration of the wider Multi-Disciplinary Team is included (not only consultants) to ensure equitable access to all elements of the service;
- equitable waiting times for all patients through the management of waiting lists by the commissioned provider regardless of the place of delivery;
- rationalisation of outreach within Health Boards to balance care as close to home as possible in the most efficient way; and
- improved joint working between local link paediatrician and tertiary team to maximise local skills, improve continuity of care, and facilitate timely repatriation.

Strategic Objective 3

A patient centred commissioning model which adds value to the treatment of children, strengthens the whole pathway approach and is commissioned across the horizontal (sub-specialty) and vertical (professional group) delivery of specialised services, supporting the transforming health care

Contracting mechanisms will need to be simplified to allow the accurate and reflective measurement of activity that also takes account of infrastructure. Also, when new funding is approved there will be a review of the contract linked to that service to support providers in the operationalising of new posts. Where a tertiary provider also provides the secondary care element of the pathway the contracts will flow through WHSSC, replicating the established commissioning model with NHS England for the population of BCUHB and Powys. This will support:

- the future planning and release of any new funding required
- transparency
- commissioning beyond the remit of WHSSC

Strategic Objective 4

Children and their families experience seamless transition across their care and treatment pathway, and between age related services.

Develop service specifications for each commissioned service (a list of all current service specifications is included in **Appendix F**), that include:

- Clear access and exclusion criteria for all specialised services,
- Clear detail for the management of patients transitioning from paediatric to adult services
- Where possible work with secondary care to develop whole pathway specifications as per the recent development of the Paediatric Orthopaedic Surgery specialised and non-specialised service specifications.

Strategic Objective 5

Specialised Paediatric services are funded prudently to ensure optimum and timely access for children, with priority being given to those services where there are deficits and constraints.

1 In order to support the implementation against the strategic objectives, a
2 5 year financial profile will be in place. All funding required to support
3 implementation will be funded through this profile and obviate the need to
4 prioritise through the WHSSC annual processes. However, it is important
5 to note that any emergent risks or new innovations that are not profiled in
6 the strategy will need to be taken through alternative WHSSC funding
7 sources.

8 9 10 **Strategic Objective 6**

Health Boards are assured that the commissioning and delivery of specialised services for children and their families have appropriate oversight structures in place.

11
12
13 The Establishment of an Oversight Group for Paediatric Services, with
14 representation from all providers, to ensure robust governance and
15 oversight of the implementation of the strategy and beyond. The
16 established Group will:

- 17
18 • oversee performance and commissioning functions to improve
19 standards of care;
20 • feed in to the WHSSC Quality and Patient Safety Committee, Management Group and Joint Committee;
21
22 • oversee and review clinical governance; and
23 • oversee the delivery against key performance indicators.
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CHAPTER 5

5.0 ENABLERS

The following enablers are the recourses and facilities required to meet the 6 strategic objectives, and in turn the strategic aim.

5.1 Digital Care

The Covid-19 pandemic has brought about a number of digital milestones, removing historic barriers in areas such as digital consultations and training. There are examples where provision has expanded locally due to support being available through digital platforms to allow improved local skills. One example is the 'Omnihub' media streaming device currently being used at Swansea Bay UHB to live stream cardiac ECHO images to the specialist team in Cardiff and Vale UHB. Further exploration and focus needs to be considered:

- Increased digital consultations where clinically appropriate to increase efficiency and capacity.
- Providing care locally with live on-hand support from the specialist centres.
- Improved access to training for all clinical teams across all levels.

5.2 Workforce

An appropriately commissioned and sustainable workforce is required to enable the implementation of the strategic objectives. The seven key themes of the [Higher Health Education and Improvement in Wales](#); A Healthier Wales: Our Workforce Strategy for Health and Social Care, will need to be considered within the workforce strategies for all providers of WHSSC commissioned services.

Theme 1 – An Engaged, Motivated and Healthy Workforce

- Embed the need for providers to ensure staff wellbeing within commissioning requirements.
- Facilitate the input of providers referring their patients to tertiary care in the development of services with the aim of maximising the use of available skills across the whole pathway of care, and ensuring care as close to home as possible. This would help with supporting flow into and out of specialised services it requires a cross system understanding of skills and competencies, across professional groups.

Theme 2 – Attraction and Recruitment

- Work with providers to consider opportunities to support the providers' recruitment and retention strategies- retention is largely a result of other aspects of people's experience in work. It is directly related to the leadership and culture of the organisation. People leave

1 because they feel overworked, underpaid, poorly treated, unable to
2 deliver good care, unable to progress, or some combination of all
3 these things.

4 5 **Theme 3 – Seamless Workforce Models**

- 6 • Support the need for a 'whole children's hospital' workforce plan –
7 services can only deliver high quality care if they have the right
8 number of staff with the right skills, and they are given adequate
9 support to work effectively.
- 10 • Considering the whole system and not just sub-specialty. The
11 commissioning of paediatric specialised services needs to be a
12 vertical (sub-specialty) and horizontal (professional group) approach
13 to not only take account of the sub-specialty but also the wider
14 staffing structures within a provider organisation with the aim of
15 supporting a 'whole professional team approach'. This will ensure a
16 more conducive and sensitive system to the practicalities of staffing
17 a safe, sustainable and attractive workforce.

18 19 **Theme 4 – Building a Digitally Ready Workforce**

- 20 • The clinically effective and efficient delivery of specialist services will
21 be dependent on a workforce that has been supported to develop the
22 required digital capabilities. These capabilities will not only be key in
23 delivering clinical care but also in maximizing education and training
24 opportunities across the region.

25 26 **Theme 5 – Excellent Education and Learning**

- 27 • Consider the impact of service developments on training needs and
28 training spaces – process required for triangulating between WHSSC,
29 HEIW and the Health Boards

30 31 **Theme 6 – Leadership and Succession**

- 32 • Embed the need for providers to ensure and supporting the 6 skill
33 areas needed for the future workplace:
 - 34 ○ Compassionate and inclusive leadership
 - 35 ○ Collective leadership
 - 36 ○ Staff and leaders meeting the care workplace needs of staff
37 (autonomy, belonging, contribution)
 - 38 ○ Team based working
 - 39 ○ Working across boundaries and professions, with other teams,
40 organisations, community
 - 41 ○ Develop skills of self-compassions

- The link between staff engagement and patient experience is well established- more engaged staff provide better, safer care and are less likely to be absent (West and Dawson 2012)

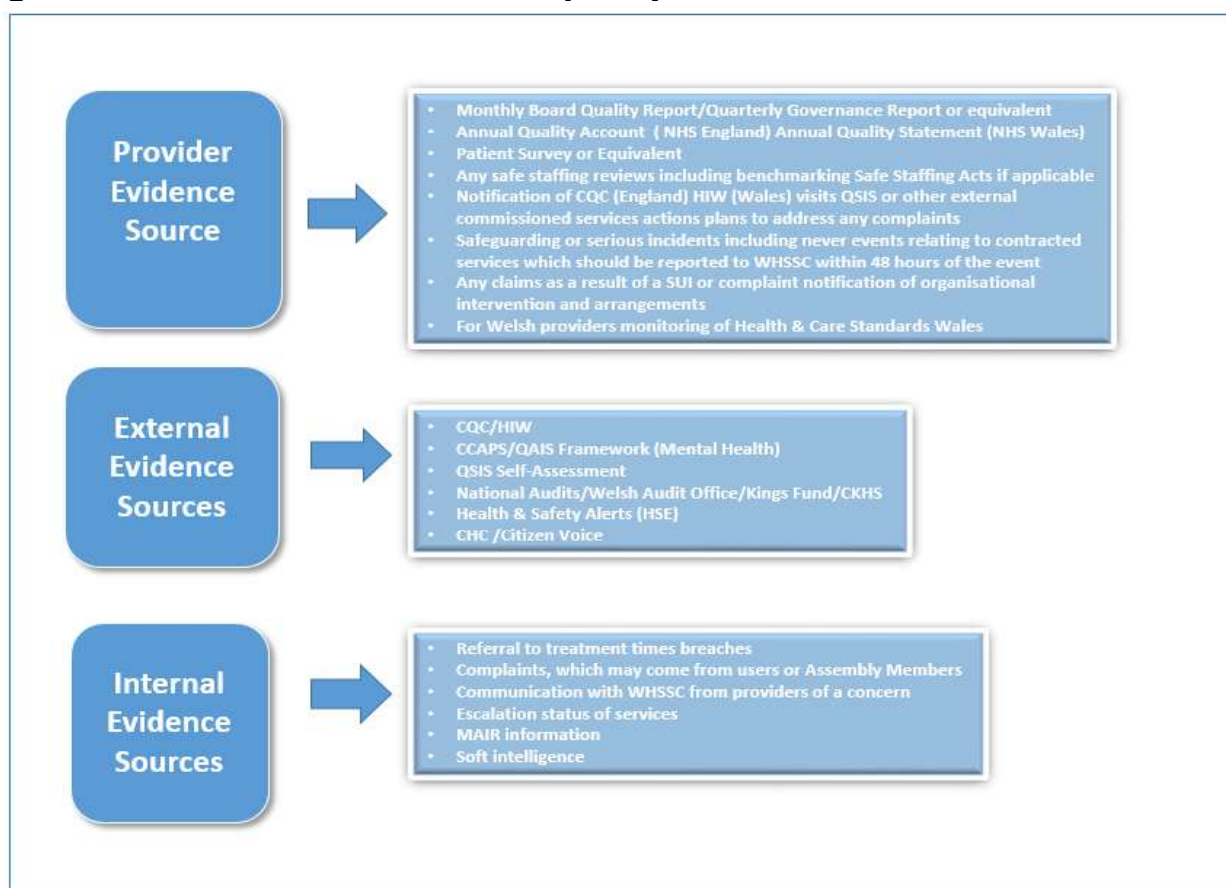
Theme 7 - Workforce Supply and Shape

- Work with teams on opportunities for workforce redesign, across all professions, including the opportunities for new roles and career development pathways. For example:
 - ~~Seizing opportunities for workforce redesign and further integration into paediatric teams for pharmacy professionals will increase the rate of service transformation. Due to established career frameworks for pharmacists and soon, pharmacy technicians, these professionals can provide medicines leadership in general and specialised paediatrics and also neonates. Opportunities for workforce redesign and development across the whole paediatric system for pharmacy, with the need for a Consultant Pharmacist to provide medicines leadership across general and specialised paediatrics and neonates. This would enable the development of a career framework for pharmacists and pharmacy technicians, which in addition to supporting retention within the specialty, can also support the development of integrated multi-professional teams and embed the principles of prudent healthcare.~~
 - Opportunities to stratify work into secondary and tertiary in surgery/anaesthesia which would enable paediatric anaesthetists to focus the utilisation of their specialist skills on the children that only they can manage, while general anaesthetists can manage the children that they have the competencies to manage.
 - Opportunities within several professional groups to integrate across specific specialties, based on the fact that they require a similar skill set. This has the potential to benefit the service - through increased resilience, the patient - through ensuring continuity during periods of leave, and the individual- through professional development opportunities.

5.3 Quality

There are a number of quality sources of evidence which are used to gather as much information as possible by which assurance is sought and can be reported or necessary action taken. A summary of these is available in **Figure 12.**

Figure 12: Sources of evidence for quality assurance



5.4 Capital

Commissioned Specialised Services will be required to ensure facilities that are fit for purpose including the physical space, capacity and equipment for both in-reach and outreach. Although WHSSC does not have the remit to fund capital projects, providers will need to demonstrate that the capital capabilities within the review of existing services and future proposals to ensure deliverability.

5.5 Co-ordinated structure to support the delivery of children's services

The development of the strategy for specialised services has highlighted the need for a more coordinated approach to the delivery of healthcare services for Children and Young people in Wales.

A structure that enables a coordinated approach will mean that the NHS will be able to make the most of its contribution to keeping people well in childhood and adolescence, and to deliver safe and high quality health services which meet the needs of Children and Young people across Wales, aligned with the principles described in the [National Clinical Framework](#).

1 The development of such a structure at this point in time, will have the
2 added benefit of ensuring a focused approach to the recovery of children's
3 services required as a result of the impact of the pandemic. This will ensure
4 that the priorities for children and young people's healthcare are aligned
5 across all levels of commissioning, and that everyone is working together
6 as one to improve these services.

7
8 The aim of such a structure would improve the variable provision of health
9 services and outcomes for Children and Young People through:

- 10
11 • Reducing unwarranted variation in health and well-being services,
12 through supporting the planning and delivery of resilient and
13 sustainable clinical services, making the most of all available capacity
14 and all available skills in order to the meet the need of the population;
- 15 • Encouraging innovation in how services are provided now and in the
16 future, and supporting service transformation;
- 17 • Providing clinical leadership to support decision making and strategic
18 planning;
- 19 • Supporting the development of nationally agreed 'seamless and
20 complete' clinical pathways for children and young people involving
21 patients and the public in strategic healthcare decisions

22
23 A co-ordinating structure would have an overarching view of service
24 provision across Wales and be able to address specific issues, all of which
25 are beyond the remit of WHSSC, by:

- 26
27 • Enabling strategic linkage of all organisations responsible for delivery
28 of healthcare to children;
- 29 • Facilitating co-operation between providers at senior clinical and
30 managerial level;
- 31 • Looking at where pathways have been effectively delivered and
32 implementing lessons learnt from these areas;
- 33 • Driving improvements to reduce variation in quality of service
34 provision across Wales;
- 35 • Gather the numerous professional standards for children's care
36 developed by Professional Bodies together in one place and to
37 support providers to deliver services against them.
- 38 • Undertaking quality assurance functions;
- 39 • Enabling effective communication between whole pathways of care
40 and other parts of the system for example PHW, HEIW and DHCW
- 41 • Driving improvements on education, training and workforce
42 development;
- 43 • Liaising with public health, social care, voluntary sector and non-
44 health organisations.

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CHAPTER 6

1 **6.0 ACTIONS**

2 The tables below set out the actions required to meet the strategic
3 objectives. There is specific reference to resource requirements and any
4 resource shortfall may require investment, a full review of existing funding
5 levels will be considered as well as any potential efficiencies prior to any
6 increase in investment to ensure the Principles of Prudent Healthcare⁶ are
7 followed.

8
9
10 **Strategic Objective 1**

There are clear access criteria and routes into and out of tertiary services for Children and their families, with increased knowledge of the remit of specialised services provision and how they fit within the whole pathway of care.

11

Ref	Action	Year	Resource
SO1-1	Formally commission specialised Paediatric Respiratory, ensuring the resource transfer of existing funding.	Year 1	Any shortfall through resource transfer will require revenue investment through strategy during the year of implementation
SO1-2	Formally commission specialised Paediatric Ophthalmology, ensuring the resource transfer of existing funding.	Year 3	Any shortfall through resource transfer will require revenue investment through strategy during the year of implementation
SO1-3	Formally commission the specialised element of a Chronic Pain pathway as part of the commissioning of a whole pathway approach by Welsh Government	Year 1	Any shortfall through resource transfer will require revenue investment through strategy during the year of implementation
SO1-4	Formally commission Paediatric Infectious Diseases, ensuring the resource transfer of existing funding.	Year 2	Any shortfall through resource transfer will require revenue investment through strategy

⁶ [Prudent healthcare principles - Bevan Commission](#)

Ref	Action	Year	Resource
			during the year of implementation
SO1-5	Formally commission high dependency care for children requiring specialist services, as part of the review of paediatric critical care led by Welsh Government*	Year 2	Any shortfall through resource transfer will require revenue investment through strategy during the year of implementation

*Currently HD care is funded through an absorbed cost within each contract line that accesses this level of care, disaggregating this from existing contract lines will be required as part of the resource transfer.

Strategic Objective 2

Children receive high quality, equitable and patient tailored care in the most appropriate environment, whether that be in-reach or outreach, with clinical teams supporting the use of advanced digital technologies and regional education and training.

Ref	Action	Year	Resource
SO2-1	Review the provision of specialist surgical services, and develop clear access criteria for each specialty (ideally aligned with a secondary care service specification for each specialty).	Year 2	No resource anticipated
SO2-2	Review the provision of specialist medical services, ensuring that all have clear access criteria and pathways that support the majority of their care being provided as close to home as possible within their resident Health Boards.	Years 1-5	No resource anticipated
SO2-3	Review the provision of outreach clinics for each specialty, to maximize the effectiveness and efficiency of the model within the available resource (2 services year 1 and 4 per year thereafter).	Years 1-5	No resource anticipated

Ref	Action	Year	Resource
SO2-4	Ensure that all members of the MDT contribute to outreach, where there is clear evidence of patient benefit (either face to face or remotely). (2 services year 1 and 4 per year thereafter).	Years 1-5	Revenue investment may be required depending on any shortfall, the investment will be incremental in line with the review schedule.
SO2-5	Ensure that the lead provider has a mechanism for recording the activity and waiting list data for all the outreach clinics, its clinicians deliver.	Year 1	No resource anticipated
SO2-6	Ensure that service specifications include the requirement for regional education and training by the provider, capitalising on recent advances in digital capabilities. (2 services year 1 and 4 per year thereafter)	Years 1-5	No resource anticipated
SO2-7	Support a process to strengthen the role of the primary paediatricians (general and community) and the wider team in leading on the care of their children with medical complexity, working in collaboration with the range of specialty paediatricians.	Years 1-5	No resource anticipated

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Strategic Objective 3

A patient centred commissioning model which adds value to the treatment of children, strengthens the whole pathway approach and is commissioned across the horizontal (sub-specialty) and vertical (professional group) delivery of specialised services, supporting the transforming health care agenda within Wales.

Ref	Action	Year	Resource
SO3-1	Review the provision of specialised services commissioned posts within each professional group, with a focus on their working within their professional team, within their specialty team and within children's services more widely across the region. (2 services year 1 and 4 per year thereafter)	Years 1- 5	Revenue costs where there are identified gaps, reconfiguration and efficiency of existing funding will be a key consideration prior to funding.

Strategic Objective 4

Children and their families experience seamless transition across their care and treatment pathway, and between age related services.

Ref	Action	Year	Resource
SO4-1	When developing new service specifications or reviewing current ones, the access criteria, the pathway into and out of specialised services and the transition pathway into adult services must be included. (2 services year 1 and 4 per year thereafter)	Years 1- 5	No resource anticipated
SO4-2	WHSSC to develop clear commissioning criteria for the transition age for paediatric to adults, taking advice from WG and Health Boards.	Year 1	No resource anticipated

Strategic Objective 5

Specialised Paediatric services are funded prudently to ensure optimum and timely access for children, with priority being given to those services where there are deficits and constraints.

Ref	Action	Year	Resource
SO5-1	The performance of each service will reviewed annually in advance of the submission of the Integrated Commissioning Plan, in order to inform funding priorities for the subsequent year.	Years 1- 5	Revenue costs to support the need for infrastructure growth or to enhance fragile services.

Strategic Objective 6

Appropriate oversight structures are in place to provide the necessary assurance on the development and delivery of services.

Ref	Action	Year	Resource
SO6-1	The WHSSC Commissioning team will develop a programme for working with each specialised service to agree the quality metrics that will underpin each domain in the STEEP Quality framework. This will determine the content of the quarterly and annual reports for each service. (2 services year 1 and 4 per year thereafter)	Years 1- 5	No resource anticipated
SO6-2	Establish the specialised paediatric services oversight group.	Year 1	No resource anticipated

6.1 Resource schedule

Financial provision for the implementation of the strategy is included within the WHSSC 2022/25 ICP.

ICP 2022/25 financial profile

Ref	2022/23	2023/24	2024/25	2025/26	2026/27
N & S Wales Paediatric Strategy	0.250	1.200	1.800	TBC	TBC

The funding requirements above are high level assumptions and require detailed consideration by the Implementation Board and will be approved by the Oversight Group, prior to approval by the WHSSC Management Group and Joint Committee. Detailed consideration of existing funding will be a fundamental consideration as well as potential efficiencies and innovative ways of working to ensure prudent but effective use of the funding. In the event of further funding being required, it will be considered through the development of each WHSSC ICP over the 5 year life span of the strategy.

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CHAPTER 7

7.0 Constraints

In order to improve children's health services in Wales, and meet the strategic objectives it is important that all the relevant organisations are working together collaboratively and see an overall picture of children's services, not just the area for which they have commissioning responsibility be that at Local Health Board level or WHSSC.

It has been identified throughout the development of the strategy that there a number of key constraints that are beyond the control and remit of WHSSC however are paramount to ensure the optimum success of its implementation.

7.1 Primary and Secondary Care infrastructure

NHS services are delivered to national priorities but are delivered locally. Variation exists in healthcare services due to a number of reasons. However, the population of Wales expects that wherever they use children's healthcare services they can receive the same high standard of care across all providers. The WHSSC Women and Children's commissioning team have identified a number of examples that indicate that there is significant variation in the quality, efficiency and/or equity of access within Wales's children's healthcare system and services. This variation is unwarranted and is driven by the limitations within healthcare services and professionals in Wales rather than by patient need. This needs urgent redress if the value and sustainability of existing NHS resources is to be maximised for the benefit of children and young people.

Examples of variation in healthcare for children:

- Local imaging provision
- Local surgical provision
- Local epilepsy service provision
- Local therapy and psychology provision
- Local high-dependency care provision
- Local anaesthetic provision

Challenges identified as a result of the lack coordinating structure and variation in healthcare provision:

- The ability to develop regional high dependency care plans for winter surge and cascade training
- The ability to develop seamless care pathways into tertiary care
- Tertiary specialists' time being taken up by managing children who should be cared for locally, and therefore having less time for the patients they are commissioned to provide care for and in parallel

1 this is resulting in the de-skilling of local providers further
2 exacerbating the issue.

- 3 • Children being transported unnecessarily to the tertiary centres.
- 4 • Children having longer lengths of stay at the tertiary centre, as a
5 result of a deficit in the required local skills that would enable them
6 to move closer to home safely.

7
8 These examples point to the need to balance paediatric skills within local
9 services and integrated networks which can provide more specialist skills.
10 In order to improve children's health services in Wales, it is important that
11 all the relevant organisations are working together collaboratively and see
12 an overall picture of children's services, not just the area for which they
13 have commissioning responsibility be that at Local Health Board level or
14 WHSSC.

15 16 **7.2 Workforce**

17 Discussions have taken place at the Workforce subgroup for the paediatric
18 strategy with a focus on how tertiary providers can be supported in
19 becoming the preferred employer for paediatric professionals, in particular
20 nurses and allied health professionals. One of the themes emerging from
21 the discussions is the need for a Workforce strategy for all Specialist
22 Centres and for Wales as a whole. The workforce strategies sit outside the
23 remit of the commissioner and are the responsibility of providing Health
24 Boards and HEIW in the context of Wales as a whole. The WHSSC
25 Commissioning Team will continue to engage with all parties to support the
26 development of each document, the strategy oversight group will also
27 require sight of them when approving any future funding to implement the
28 strategic objectives.

29 30 **7.3 Transition**

31 The key for both young people transitioning to adult care, or entering adult
32 care is that there are services that they can access. There is variation in
33 terms of service availability across the specialties as well as the
34 commissioning arrangement. Some services are well developed and
35 commissioned by WHSSC however there are a number of adult services
36 that patients will transition to that are outside the remit of WHSSC and are
37 often less developed, it is a notable constraint. The focus and priority needs
38 to be on supporting the development of the adult service to meet the needs
39 of the patient population whether this as at HB, regional or an All Wales
40 level.

1 Abbreviations

ABUHB	Aneurin Bevan University Health Board
BAHA	Bone Anchored Hearing Aid
BCUHB	Betsi Cadwaladr University Health Board
BMT	Bone Marrow Transplant
C&VUHB	Cardiff and Vale University Health Board
CHfW	Children's Hospital for Wales
CLP	Cleft Lip and Palate
CTMUHB	Cwm Taf Morgannwg University Health Board
DGH	District General Hospital
ENT	Ear Nose and Throat
GPS	General Paediatric Surgery
GIRFT	Getting it Right First Time
HB	Health Boards
HDU	High Dependency Unit
HEIW	Higher Education Improvement Wales
IPFR	Individual Patient Funding Request
IMD	Inherited Metabolic Disease
ICP	Integrated Commissioning Plan
LA	Local Authority
LHB	Local Health Boards
MDT	Multi-disciplinary Team
NCCHD	National Community Child Health Database
ONS	Office of National Statistics
PICU	Paediatric Intensive Care Unit
PHW	Public Health Wales
QPS	Quality and Patient Safety
SDR	Selective Dorsal Rhizotomy
SBUHB	Swansea Bay University Health Board
WHSSC	Welsh Health Specialised Services Committee

APPENDIX A - BROADER POLICY CONTEXT WITHIN WHICH THE STRATEGY IS SET

Strategic Context

The main focus of this Strategy is the commissioning of Specialised Paediatric Services. It is however important to note that it is underpinned by the Welsh Government Strategy: A Healthier Wales our plan for a healthier Wales, and a number of service specific standards published by Welsh Government.

Ministerial Priorities

In July 2021, eight priorities were issued by the Minister for Health and Social Services:

- Maintain Response to COVID-19
- NHS Recovery
- Working Alongside Social Care
- A Healthier Wales – Strategy for Health and Social Care
- Financial Discipline for NHS Wales
- Mental Health – Clinical and Broader Society
- Supporting The Health and Care Workforce
- Population Health and Health Equity

The priorities focus on improving population health and reducing health inequalities, with a concerted shift to wellness, outcomes and ensuring equity of access. This direction acknowledges and reconfirms that [A Healthier Wales](#) remains the ambition for Wales, supported by implementation of the [National Clinical Framework for Wales \(2021\)](#) and framed by the Wellbeing of Future Generations Act.

The WHSSC Integrated Commissioning Plan 2022-25 (ICP) sets out WHSSC's commitment and contribution to the achievement of these priorities.

The COVID-19 Pandemic

The WG document [Health and Social Care in Wales – COVID-19: Looking Forward](#) was published in March 2021 and describes the significant impact of COVID-19 on society and on health and social care services, identifies some of the opportunities and risks as we look ahead to the next phase of the pandemic response and towards recovery and sets out a range of priorities to be pursued in the coming months and years.

A Healthier Wales

[A Healthier Wales: our Plan for Health and Social Care](#) is the ten year strategy for health and social care in Wales and was published in 2018 in order to respond to a Parliamentary Review of the Long Term Future of Health and Social Care. It sets out a long-term vision that everyone in Wales should have longer, healthier and happier lives. It proposes a whole-system approach to health and social care which is equitable, and where services are designed around individuals and groups based on their unique needs and what matters to them, as well as quality and safety outcomes.

WHSSC is ambitious about its role in supporting the bold agenda set out in A Healthier Wales. Putting quality and safety above all else is the first NHS Wales core value. This focus has been strengthened more recently through the [Health and Social Care \(Quality and Engagement\) \(Wales\) Act \(2020\)](#), the [National Clinical Framework for Wales \(2021\)](#) and the [Quality and Safety Framework \(2021\)](#). Collectively these set out an aspiration for quality-led health and care services, underpinned by prudent healthcare principles, value-based healthcare and the quadruple aim.

The Transition and Handover Guidance (WG) – February 2022

The recently published guidance provides clarity on the management, handover and accountability of healthcare services for children and young people during their transition from Children's to adults services. The guidance defines Children's Health Services as a service that provides health care to an infant, child and young person generally up to their 16th birthday.

Quality and Safety Framework: Learning and Improving 2021

The framework provides an overview of what quality looks like, highlights the key principles that underpin it and the arrangements that need to be in place to be assured of high quality services at all times. There is a strong focus on quality and safety from the Covid-19 pandemic, trying to understand the true harm that has occurred over the past eighteen months and, moving forward, to ensure the needs of the population are met.

Closing the Gap

The Joint Report developed by the King's Trust and the Nuffield Trust sets out a series of policy actions that with funding will aim to create a sustainable staffing model to help support the elimination of nursing shortages.

The NHS Wales Health and Care workforce strategy

Developed jointly by HEIW and SCW, the strategy sets out the vision, ambition and approaches that put wellbeing at the heart of the plans for the NHS and social care workforce in Wales.

Paediatric Standards in Wales

A series of service specific standards for specialised healthcare services for the children and young people of Wales were developed between 2005 and 2009 and are underpinned by the overarching document, [All Wales Universal Standards for Children and Young People's Specialised Healthcare Services](#).

The NHS Wales Health Assessment Framework for Looked after Children

The framework has been developed by the National Safeguarding Team in collaboration with Health Boards across Wales. The framework provides standards of good practice for Health Boards working with children who are currently Looked After by the local authority.

The Mental Health Specialised Services Strategy 2022-2028

The draft strategy has recently been shared with stakeholders for feedback and is due to be published in the Winter of 2022.

APPENDIX B – PROGRAMME STRUCTURE

Programme Board

Purpose

The purpose of the Programme Board is to oversee the process for the conduct of the review and to agree the report and recommendations to the Joint Committee.

Membership

WHSSC Director of Planning (Chair)
WHSSC Assistant Director of Planning
WHSSC Associate Medical Director Women and Children
Clinical Board Director of Paediatric Services in both Cardiff and Vale University Health Board and Betsi Cadwaladr University Health Board
Director of Paediatric Services or equivalent in both Cardiff and Vale University Health Board and Betsi Cadwaladr University Health Board
Commissioner representatives from each of the 7 Health Board
Associate Chief Operating Officer from Alder Hey Children's Hospital

Programme Management Team

Purpose

The purpose of the Programme Management Team is to co-ordinate and deliver on the programme outputs and requirements, as well as overseeing the process for the conduct of the review and to agree the report and recommendations to the Programme Board.

Membership

WHSSC Assistant Director of Planning (Chair)
WHSSC Assistant Director of Finance
WHSSC Associate Medical Director Women and Children
WHSSC Planner for Women and Children
WHSSC Planner for North Wales
WHSSC Information Analyst
WHSSC Assistant Planner

Service Modelling Group

Purpose

The purpose of the Service Modelling Group to develop the overarching model for specialised Paediatric Services in Wales.

Membership

WHSSC Assistant Director of Planning (Chair)
WHSSC Assistant Director of Finance
WHSSC Associate Medical Director Women and Children
WHSSC Planner for Women and Children
WHSSC Quality Lead
Chair of each of the sub-groups (x6)
Clinical Director of Paediatric Services for all 7 Health Boards in Wales

Collective Commissioning Sub-group

Purpose

The purpose of the Collective Commissioning sub-group is to develop a list of potential services that are to be considered for routine commissioning by WHSSC and to consider the appropriateness of the existing commissioned services.

Membership

Director of Finance, WHSSC
Associate Programme Director for Tertiary and Specialist Services Planning Partnership, C&V and Swansea Bay
Assistant Director of Finance, WHSSC
Assistant Director of Planning, WHSSC
Commissioning Representative from all 7 Health Boards
NHS England commissioning

Workforce Sub-group

Purpose

The purpose of the Workforce Working Group is to develop the principles and workforce model required to stabilise all specialties providing Specialised Services for the population of Wales.

Membership

WHSSC Associate Medical Director
Representation from the All Wales Nursing Group
Representation from the All Wales Therapies Group
Head of school for Paediatrics at HEIW
Representation from English Providers
Representation from all professional groups at CHFW

Finance Sub-group

Purpose

The purpose of the Finance sub-group is to consider the current financial mechanisms in place for the commissioning of paediatric services and the cost implications of the implementation of the Paediatric Strategy.

Membership

Assistant Director of Finance, WHSSC (Chair)
Finance Representative from all 7 Health Boards

Quality and Governance Sub-group

Purpose

The purpose of the Quality and Governance sub-group is to consider the current quality assurance measures that are in place and to develop robust structures for commissioned services.

Membership

Clinical Board Director for Children and Womens Services, Cardiff and Vale UHB
Head of Quality and Patient Care, WHSSC
Associate Medical Director, WHSSC
Quality Lead, WHSSC
Quality Representative with a Paediatric remit from 7 Health Boards
Quality Representation from Alder Hey Children's Hospital, Bristol Royal Hospital for Children and Birmingham Children's Hospital

North Wales Sub-group

Purpose

The purpose of the Local Provision of North Wales Specialised Services sub-group is to consider the current commissioning arrangements for services accessed by the North Wales population and to consider opportunities to strengthen local provision.

Membership

Medical Director, WHSSC (Chair)
Medical Director, BCUHB
Clinical Lead for Paediatric Services BCUHB
Commissioning Manager, BCUHB
Finance Lead, BCUHB
Quality Lead, WHSSC
Associate Medical Director, WHSSC
Assistant Director of Finance WHSSC

Surgery in Children work-stream

Purpose

The Paediatric Surgery work-stream will work on defining Specialised Surgery in Children and clinical criteria for general paediatric procedures that require specialist input due to complex needs.

Information work-stream

Purpose

The information work-stream will ensure robust data informs and underpins all recommendations within the strategy.

APPENDIX C – THE RIGHTS OF A CHILD⁷

KNOW YOUR RIGHTS

The United Nations Convention on the Rights of the Child, or the UNCRC, is a list of rights that all children and young people in Wales and across the world have.

Article 1:
Everyone under 18 has these rights.

Article 2:
All children have these rights no matter what. All children should be treated equally.

Article 3:
Adults should always do what is best for you.

Article 4:
The Government should make sure that all children and young people get these rights.

Article 5:
The Government should respect the right of your family to help you know about your rights.

Article 6:
You have the right to life, to grow up and reach your full potential.

Article 7:
You have the right to a name and a nationality.

Article 8:
You have the right to an identity.

Article 9:
You have the right to live with your parents, if this is what's best for you.

Article 10:
You have the right to see your family even if they live in a different country.

Article 11:
You have the right not to be kidnapped or taken out of the country illegally.

Article 12:
You have the right to be listened to and taken seriously.

Article 13:
You have the right to find out and share information, and say what you think.

Article 14:
You have the right to practise your own religion, as long as you're not stopping people from enjoying their rights.

Article 15:
You have the right to meet with friends and join groups.

Article 16:
You have the right to privacy.

Article 17:
You have the right to honest information from the media that you can understand, as long as it's safe.

Article 18:
You have the right to be brought up by both parents, if possible.

Article 19:
You have the right to be protected from being hurt or badly treated.

Article 20:
You have the right to be looked after properly if you can't live with your own family.

Article 21:
If you can't live with your parents, you have the right to live in the best place for you.

Article 22:
If you are a refugee, you have the same rights as any other child in the country.

Article 23:
If you are disabled, you have the right to special care and support so that you can lead a full and independent life.

Article 24:
You have the right to clean water, healthy food, a clean environment and good healthcare.

Article 25:
If you're not living with your family, you have the right to a regular check on how you're being cared for.

Article 26:
You have the right to support from the Government if your family hasn't got enough money to live on.

Article 27:
You have the right to a proper house, food and clothing. Governments must help families who cannot afford to provide this.

Article 28:
You have the right to an education.

Article 29:
You have the right to be the best you can be. Education must help you develop your skills and talents to the full.

Article 30:
You have the right to speak your own language and follow your family's way of life.

Article 31:
You have the right to relax and play.

Article 32:
You have the right to be protected from doing dangerous work.

Article 33:
You have the right to be protected from dangerous drugs.

Article 34:
Nobody should touch you in ways that make you feel uncomfortable, unsafe or sad.

Article 35:
You have the right to not be abducted, sold or trafficked.

Article 36:
You have the right to be kept safe from things that could harm your development.

Article 37:
You have the right not to be punished in a cruel or hurtful way.

Article 38:
You have the right to be protected during a war and not to fight in the army if you're under 15.

Article 39:
You have the right to special help if you've been hurt or badly treated.

Article 40:
You have the right to legal help and to be treated fairly if you've been accused of breaking the law.

Article 41:
If the laws in your country protect you better than the rights in this list, those laws should stay in place.

Article 42:
The Government must let children and families know about children's rights.

Articles 43-54:
These articles are about how adults and the Government must work together to make sure all children get their rights.

Do you need to talk to us about a problem?

Our Investigations and Advice service is free and confidential. It's there to help and support children and their families. Get in touch to find out how we can help.
Phone: 0808 801 1000 Email: advice@childrenscommissioner.wales

Get in touch

Website: www.childrenscommissioner.wales
Email: post@childrenscommissioner.wales
@ @f @childcomwales

⁷ [CCfW A2 Rights Poster ENGLISH AW \(childcomwales.org.uk\)](http://CCfW A2 Rights Poster ENGLISH AW (childcomwales.org.uk))

1 **APPENDIX D – INCIDENCE RATES OF SPECIFIC**
2 **CONDITIONS**

Cleft Lip and Palate
<p>A cleft lip and/or palate (CLP) is the most common facial birth defect in the UK, affecting around one in every 700 babies.</p> <p>It is the most common congenital abnormality in the cranio-facial region. Incidence rates are approximately 1.6 per 1,000 but this can vary year to year.</p> <p>The incidence of CLP in the UK can be summarised as:</p> <ul style="list-style-type: none">• Cleft Palate only 45%• Cleft Lip (+/- alveolus) only 23%• Unilateral Cleft Lip and Palate 22%• Bilateral Cleft Lip and Palate 10%⁸
Paediatric BAHA and Cochlear
<p>Approximately 370 children in England and 20 children in Wales are born with permanent severe to profound deafness each year.</p> <p>Around 90% of these children have 2 parents who can hear. About 1 in every 1,000 children is severely or profoundly deaf at 3 years old. This rises to 2 in every 1,000 children aged 9 to 16 years.</p> <p>There are approximately 613,000 people older than 16 years with severe to profound deafness in England and Wales.</p> <p>In the UK around 3% of people older than 50 and 8% of those older than 70 years have severe to profound hearing loss.</p> <p>Approximately 40% of children who are deaf and 45% of people younger than 60 years who are deaf have additional difficulties, such as other physical disabilities.⁹</p>
Paediatric Cystic Fibrosis
<p>Cystic fibrosis is a multi-system genetic disorder affecting the lungs, pancreas, liver and intestine. It results from mutations affecting a gene that encodes for a chloride channel called the cystic fibrosis</p>

⁸ <https://whssc.nhs.wales/commissioning/whssc-policies/paediatric-services/cp186-cleft-lip-and-or-palate-including-non-cleft-velopharyngeal-dysfunction-all-ages/>

⁹ [NHS commissioning » Women and Children \(england.nhs.uk\)](#)

transmembrane conductance regulator (CFTR), which is essential for the regulation of salt and water movements across cell membranes.

The UK Cystic Fibrosis Registry [Annual Data Report 2018](#) shows that 10,509 people in the UK have cystic fibrosis, with 222 people newly diagnosed with cystic fibrosis in the year¹⁰.

Paediatric Endocrinology

Endocrine conditions, which vary in incidence from 1 in 500 to <1 in 15,000 in the UK, require specialist care by a paediatric endocrinologist and an associated dedicated multi-professional team within a tertiary centre, and/or shared care with a District General Hospital through an established network.¹¹

Paediatric Gastroenterology

The prevalence/incidence varies by condition. Examples include:

- Inflammatory bowel disease has a prevalence of 30 cases per 100,000, children under age 16 years, with an incidence of 8-10 new cases per 100,000.
- Diagnostic endoscopy rates vary around 200 per 100,000 population under age 17 years.

Intestinal failure (parenteral nutrition/intravenous feeding) >28 days) = 100-120 million children under 16 years of age.¹²

Paediatric Nephrology

The number of children reaching ESRF per annum is around 2 per million of the total population. In Wales this is approximately 6 new cases per year. There are approximately 50 children on RRT in Wales at any one time, many with a renal transplant. Current management of ESRF in children has resulted in improved growth and Quality Adjusted Life Years (QALY).¹³

Paediatric Neurology (including Ketogenic Diet and Epilepsy Surgery)

¹⁰ [NHS commissioning » Women and Children \(england.nhs.uk\)](#)

¹¹ <https://whssc.nhs.wales/commissioning/whssc-policies/paediatric-services/cp186-cleft-lip-and-or-palate-including-non-cleft-velopharyngeal-dysfunction-all-ages/>

¹² <https://whssc.nhs.wales/commissioning/whssc-policies/paediatric-services/cp186-cleft-lip-and-or-palate-including-non-cleft-velopharyngeal-dysfunction-all-ages/>

¹³ Welsh Assembly Government (2009) [All Wales Nephrology Standards for Children and Young People's Specialised Healthcare Services](#)

It has been estimated that 2%-3% of the child population will have some level of disability leading to additional health and educational needs. The vast majority of child disabilities are neurological in origin with paediatric epilepsy the most common neurological disorder affecting about 0.7% of all children. Approximately one third of child neurological disease requires specialised services, although this figure will show local variation.

Non-traumatic acute encephalopathy has an incidence of approximately 50 per 100,000 per year. Metabolic disorders may present either as an acute encephalopathy or as long term neurological illness. Individual conditions are rare (e.g. phenylketonuria (PKU), 8.5 per 100,000. Many of the neuromuscular conditions are rare but all lead to significant morbidity. The overall prevalence of an inherited neuromuscular disease may well exceed 33/100,000 and a large proportion of these will be in the paediatric age group. 4 per 100,000 children aged 0-16 years will be diagnosed with a tumour of the central nervous system.¹⁴

Paediatric Oncology

Around 41% are leukaemias and lymphomas and 25% are brain tumours, with the remaining conditions comprising a wide range of solid tumours.

In Great Britain, the world age-standardised incidence rate has increased by more than two fifths (43%) since the late 1960s, from 107 cases per million children in 1966 – 1970 to 152 cases per million in 2001 – 2005. Between 1966 and 2000 there has been a statistically significant average annual increase of almost 1% per year, although this varies between 0.5% and 2.5% per year by tumour type. The literature suggests a plateau has been reached in childhood cancer incidence rates from the mid-1990s onwards.

Cancer in children is rare, with about one in 600 children developing a cancer by age 15 years. There are approximately 1,400 new cases of cancer among children 0-15 years in the UK each year; an annual incidence rate of approximately 1:7700. Proportionately, this would suggest an annual incidence in Wales of approximately 70 children per year.

Across the 0-19 age range, the highest incidence of cancer is among children 0-4 years, reducing among children 5-14, and rising again

¹⁴ https://www.england.nhs.uk/wp-content/uploads/2018/09/E09-S-b-Paediatric-Neurosciences-Neurology.pro_2013.04.v2.pdf

among teenagers over 15 years. The incidence of childhood cancer in each region is similar throughout the UK.¹⁵

Paediatric Rheumatology

The prevalence of different rheumatological conditions differs depending on factors such as local demographics and ethnic composition. Many of the diseases are very rare. Even the more common JIA has incidence of 1 in 10,000 and a prevalence of 1 in 1,000. Conditions such as Juvenile Dermatomyositis (JDM) are extremely rare. It is estimated there are:

- 12,000,000 children, 12,000 children with JIA
- half of these will go on to have arthritis in adulthood
- 1 in 3 will not have arthritis in adulthood but will have sustained permanent damage to one or more joints¹⁶

1

¹⁵ [NHS commissioning » Women and Children \(england.nhs.uk\)](https://www.england.nhs.uk/commissioning/women-and-children/)

¹⁶ <https://whssc.nhs.wales/commissioning/whssc-policies/paediatric-services/cp186-cleft-lip-and-or-palate-including-non-cleft-velopharyngeal-dysfunction-all-ages/>

APPENDIX E – QUALITY ASSURANCE SUPPORTING INFORMATION SYSTEMS

NHSE Quality Surveillance Information System

A large percentage of the services WHSSC commission are from NHS England providers. Sharing of intelligence and access to assurance systems and processes not only prevents duplication but utilises the workforce and resources to compliment the systems and processes within WHSSC. The Quality Surveillance Team (QST) which is now part of NHS Improvement, supports the monitoring of quality of all specialised commissioning services in England. Information on the quality of services is made available through a single portal known as the Quality Surveillance Information System (QSI) which is moving to a new reporting platform known as Model Hospital. This supports benchmarking and provides the platform for the reporting on specialised service quality dashboards. These are used to gain assurance from a provider perspective through the self-assessment process but also through access to the service dashboards capturing the key quality indicators agreed through the service specifications. Bringing NHS Wales providers on line will further enhance national benchmarking of specialised services and enable further understanding around patient outcomes.

The Once for Wales Concerns Management System (OfWCMS)

OfWCMS is a new approach to how NHS organisations in Wales consistently report, record, learn and monitor improvements following incidents, complaints, claims and other adverse events that occur in healthcare. By bringing all this vital data together there is an opportunity for a platform that allows shared learning and will help to improve patient safety as well as patient experience. Though in early stages there is potential that data captured from OfWCMS can be used by health organisations as part of their routine quality management processes.

APPENDIX F – WHSSC SERVICE SPECIFICATIONS

Service	Policies	Service Specification	Related
Cleft Lip and Palate		CP186	
Paediatric BAHA and Cochlear	CP35		
Paediatric Cystic Fibrosis	PP198	CP194 in development	CP193 (Adults and Young People)
Paediatric Cardiology			
Paediatric Endocrinology		CP163	
Paediatric Gastroenterology	CP211 in development		
Paediatric Immunology		CP78	
Paediatric Inherited Metabolic Disease	CP55		
Paediatric Intensive Care			
Paediatric Nephrology		CP169	
Paediatric Neurology		CP213 in development	
Paediatric Neuro-rehabilitation		CP160	
Paediatric Neurosurgery			
Paediatric Oncology			
Paediatric Rheumatology		CP172 in development	
Specialised Paediatric Surgery	CP171 planned		
Specialised ENT surgery	CP231 in development		
Specialised Orthopaedic surgery	CPXXX in development		
Specialised Paediatric Respiratory			
Paediatric Radiology		CP161 in development	



Report Title	Cochlear Implant and Bone Conduction Hearing Implant Hearing Device Service – Engagement Process			Agenda Item	3.5
Meeting Title	Joint Committee			Meeting Date	06/09/2022
FOI Status	Open				
Author (Job title)	Specialised Planner Neurosciences and LTC				
Executive Lead (Job title)	Director of Planning				
Purpose of the Report	<p>This report has a dual purpose:</p> <ul style="list-style-type: none">Initially it presents an update on management group discussions and asks Joint Committee to support the management group recommendation.Secondly it presents the materials and process for a period of targeted engagement with regard the future configuration of the South Wales Cochlear Implant and Bone Conduction Hearing Implant Device Service.				
Specific Action Required	RATIFY <input type="checkbox"/>	APPROVE <input checked="" type="checkbox"/>	SUPPORT <input type="checkbox"/>	ASSURE <input checked="" type="checkbox"/>	INFORM <input checked="" type="checkbox"/>
Recommendation(s): Members are asked to: <ul style="list-style-type: none">Support management group recommendation,Agree the process to be followed (as advised by the Board of CHCs),Agree the content of the engagement materials as the basis of targeted engagement,Advise on processes for individual Health Boards; andNote the EQIA.					

COCHLEAR IMPLANT AND BONE CONDUCTION HEARING IMPLANT DEVICE SERVICE – ENGAGEMENT PROCESS

1.0 SITUATION

This report has a dual purpose:

- Initially it presents an update on management group discussions and asks Joint Committee to support the management group recommendation.
- Secondly it presents the materials and process for a period of targeted engagement with regard the future configuration of the South Wales Cochlear Implant and Bone Conduction Hearing Implant Device Service.

2.0 BACKGROUND

Urgent temporary arrangements have been in place for the provision of Cochlear services from a single centre since 2019. Recent work has been undertaken to develop an options appraisal on the future commissioning of the service, with the scope of that consideration also including the provision of BAHA.

At the WHSSC Joint Committee (JC) meeting held on 12 July 2022, members received a report presenting the process and outcome of a recent review of tertiary auditory services and the planned next steps for the south Wales Cochlear Implant and BAHA Hearing Implant Device Service. The preferred commissioning options as the basis of engagement/consultation were noted and it was agreed that this option and the process to arrive at this option should be considered further through the Management Group (MG) meeting on the 28 July 2022. The outcome of this scrutiny could then be considered virtually or at a future extra-ordinary meeting of the JC if required.

A more detailed report describing the process to arrive at the preferred option was presented to the MG meeting 28 July 2022 and the outcome was that *members supported the preferred commissioning option of a single implantable device hub for Cochlear and BAHA for both children and adults with an outreach support model.* The report presented to the management group is attached at Appendix 1.

Advice has been sought from the Board of Community Health Councils, who advise a period of targeted engagement with patients, families and affected stakeholders. Engagement materials, and the approach will be considered through the Exec of each CHC prior to commencement. (Note dates run just

after Joint Committee). Engagement leads in affected Health Boards have also been kept informed.

2.0 ASSESSMENT

Process

The proposed process for the targeted engagement is:

- Letter to all patients/carers, including engagement materials, and outlining current position, case for change, options that have clinically been considered and a preferred option of future delivery
- Letter to all clinical teams including engagement materials, and outlining current position, case for change, options that have clinically been considered and a preferred option of future delivery
- Publication of the engagement process and materials on Health Board websites
- Cascade of documentation through Voluntary Councils for broader stakeholder view

Materials

In order to support the process, the following materials have been produced, and are attached for approval:

- Engagement document (Appendix 2)
- Draft Equality Impact Assessment (Appendix 3)

Further to approval of the core engagement document, an easy read version will be developed, as well as a questionnaire to aid response. Information gleaned through the engagement exercise will aid further completion of the EQIA.

Timeline

The following timeline for targeted engagement is proposed, noting that a period of consultation may be required following this stage:

Governance Process	Date	Action
Joint Committee Meeting	6 th September 2022	Present core engagement documents for sign off as basis of engagement
Health Board Meetings	September 2022	Seek support from Boards on engagement with Health Board residents (<i>note report will include CHC view from the HB area</i>)
Community Health Council meeting	19 th October 2022	Final update based on JC and HB views
Engagement Process	24 th October 2022	6 week engagement
Engagement Finishes	5 th December 2022	Consideration of comments and any associated mitigations
Health Board Meetings	January 2023 (tbc)	Outcome of the Engagement process
Community Health Council meeting	19 th January 2023 (tbc)	Outcome of the Engagement process

Next Steps

Next steps include:

Welsh translation – Engagement documentation will be available in both Welsh and English, as well as in other languages upon request.

Clinical Reference Group – Throughout the work on the options appraisal, commitment was given to develop a Clinical Reference Group that would continue to evolve thinking throughout the engagement process. The first meeting of this group will take place late September/early October to allow for adequate notice for clinical colleagues.

Discussions with affected staff - discussion has remained ongoing with colleagues in Cwm Taf Morgannwg, regarding staff who moved with the service during 2019 under honorary contract agreement. Staff have been notified in advance that a targeted engagement process is to commence within the timescales shared within this paper.

Update EQIA – Through the targeted engagement, information will be gathered that will enable further development of the EQIA.

3.0 RECOMMENDATIONS

Members are asked to:

- **Support** management group recommendation,
- **Agree** the process to be followed (as advised by the Board of CHCs),
- **Agree** the content of the engagement materials as the basis of targeted engagement,
- **Advise** on processes for individual Health Boards; and
- **Note** the EQIA.

Governance and Assurance	
Link to Strategic Objectives	
Strategic Objective(s)	Development of the Plan Choose an item. Choose an item.
Link to Integrated Commissioning Plan	
Health and Care Standards	Safe Care Effective Care Timely Care
Principles of Prudent Healthcare	Care for Those with the greatest health need first Reduce inappropriate variation Choose an item.
NHS Delivery Framework Quadruple Aim	People in Wales have improved health and well-being with better prevention and self-management Choose an item. Choose an item. Choose an item.
Organisational Implications	
Quality, Safety & Patient Experience	To ensure that the delivery model will provide a safe and sustainable hearing implant device service, which meets national standards for the south Wales region.
Finance/Resource Implications	There are no resource implications.
Population Health	To ensure all users of the Hearing Implant Device centre have equal access to surgery and provide life management and care for patients offering care closer to home.
Legal Implications (including equality & diversity, socio economic duty etc)	There are no known legal, equality and diversity implications.
Long Term Implications (incl WBFG Act 2015)	Ensuring patients physical and mental well-being is maximised in which choices that will benefit future health.
Report History (Meeting/Date/Summary of Outcome)	Corporate Directors Group Board 18 th August 2022
Appendices	<ul style="list-style-type: none"> Management group report (Appendix 1)

- | | |
|--|--|
| | <ul style="list-style-type: none">• Engagement document (Appendix 2)• Equality Impact Assessment (Appendix 3) |
|--|--|



In Report Title	South Wales Cochlear Implant and BAHA Hearing Implant Device Service			Agenda Item	3.3
Meeting Title	Management Group			Meeting Date	28/07/2022
FOI Status	Open				
Author (Job title)	Specialised Planner for Neurosciences and LTC Assistant Director of Planning				
Executive Lead (Job title)	Director of Planning				
Purpose of the Report	The purpose of this report is to present the process and outcome of a recent review of tertiary auditory services in south Wales, present the preferred commissioning model arising from the process and the planned next steps for the engagement and consultation on the preferred model for the South Wales Cochlear Implant and BAHA Hearing Implant Device Service.				
Specific Action Required	RATIFY <input type="checkbox"/>	APPROVE <input type="checkbox"/>	SUPPORT <input checked="" type="checkbox"/>	ASSURE <input type="checkbox"/>	INFORM <input checked="" type="checkbox"/>
Recommendation(s): Members are asked to: <ul style="list-style-type: none">• Note the report,• Note and receive assurance on the assessment process inclusive of a) clinical options appraisal, b) external review against standards and c) financial options appraisal,• Note the outcome of the clinical options appraisal for the south Wales centres, the external assessment of the options and the financial appraisal,• Support the preferred commissioning option as the basis of engagement/consultation; and• Note that based on the Management Group's recommendation the required engagement/consultation documentation will be submitted to the September meeting of the Joint Committee.					

SOUTH WALES COCHLEAR IMPLANT AND BAHA HEARING IMPLANT DEVICE SERVICE

1.0 SITUATION

The purpose of this report is to present the process and outcome of a recent review of tertiary auditory services in south Wales, present the preferred commissioning model arising from the process and the planned next steps for the engagement and consultation on the preferred model for the South Wales Cochlear Implant and BAHA Hearing Implant Device Service.

2.0 BACKGROUND

Cochlear services are commissioned from two centres in South Wales, the University Hospital of Wales (UHW) in Cardiff and the Princess of Wales (POW) Hospital in Bridgend. The services are provided to the populations of the following Health Board (HB) areas:

- Cwm Taf Morgannwg
- Cardiff & Vale
- Aneurin Bevan
- South Powys
- Swansea Bay
- Hywel Dda

During 2019, an urgent temporary service change was made as a result of the service provided from Bridgend becoming unsustainable, with all patients being moved to Cardiff. The staff associated with the service were also temporarily moved in order to support the service. At that time, there were plans to implement a formal service change, however the emergence of the pandemic resulted in a delay to the conclusion of the preparatory work and subsequent progress into formal engagement and consultation. Staff who moved with the service, enabled by honorary contracts, remain in a temporary situation and there is a desire to formalise their arrangements.

BAHA services for the south Wales population are currently provided from three HB's: Swansea Bay, Cardiff and Vale and Aneurin Bevan. Across all three centres there are 16 to 20 BAHAs provided each year. This means that each centre delivers around 6 BAHAs per year.

Work commenced in September 2021 to develop the preferred commissioning model for the delivery of robust, high quality tertiary audiometry services that meet the required standards.

A summary of the process and outcomes, as well as a recommendation on a preferred future commissioning option for all specialist hearing services are outlined in the assessment section of this report, with the detailed write ups available at **Appendices 1, 2 & 3.**

Patients from North Wales and North Powys are not affected by the proposal.

3.0 ASSESSMENT

3.1 Clinical Options Appraisal

A Clinical options appraisal workshop took place on the 9 September 2021, with invitations extended to clinical and planning colleagues from HB's affected by any proposed change. Five options were considered and participants had the opportunity to consider and influence both criteria and weightings, before being asked to score each option against the weighted criteria.

The options were:

	OPTION	DESCRIPTION
A	Do nothing	2 Cochlear hubs for adults and children 3 BAHA hubs for adult and children
B	Central Cochlear Distributed BAHA	A Single hub (with outreach) for Cochlear 3 x BAHA hubs for both adults and children
C	Central Cochlear, Central Paeds BAHA, distributed Adult BAHA	1 x Cochlear hub with Cochlear outreach 1 x BAHA hub (paediatrics) 1 x BAHA hub (adult)
D	Single implantable device hub	1 x single centre for Cochlear and BAHA for both children and adults with an outreach support model
E	1 cochlear hub (Children and adults) 1 BAHA hub (Children and adults)	1 x single centre for BAHA (children and adults) 1 x single centre for Cochlear (Children and adults)

All participants were asked to consider the options against the following standards, which were shared and discussed at the session:

- Cochlear Implant Services for Children and Adults- Quality Standards 2018,
- NHSE Clinical Commissioning Policy: Bone conducting hearing implants for hearing loss (all ages)(2016); and
- NHSE Clinical Commissioning Policy: Bone anchored hearing aids (2013).

Following the application of the weighted criteria by each person present, the preferred option from the clinical options appraisal was **Option B**. A detailed write up of the process is presented at **Appendix 1.**

The outcome of the workshop was reported to the WHSSC Corporate Directors Group Board (CDGB) who requested assurance that the preferred option from the clinical option appraisal met all of the standards and did not increase the cost of the current model.

To gain this assurance the CDGB asked for an external assessment of all of the options against the standards and the Bristol Specialist Hearing Centre (BSHC) was commissioned to undertake this assessment

A letter was sent to all of those invited to the Clinical Option Appraisal Workshop copied to Directors of Planning on 17 November 2021 thanking them for their attendance and advising them of the next steps to include an external appraisal of the options and a financial appraisal. This letter is attached at **Appendix 2**.

3.2 External Assessment

In order to consider the options against the relevant service standards, an external assessment was undertaken by members of the BSHC. The same options and criteria as those used in the clinical options appraisal were used.

Through an external assessment of the options against the standards, the only option considered to meet all of the standards was option D. The detailed assessment is presented at **Appendix 3**.

3.3 Financial Assessment

The budget for the BAHA and Cochlear service is almost £5m, with the majority of investment going to Cardiff and Vale University Health Board (CVUHB). A financial assessment of each of the options was undertaken using contract values, costing returns and service proformas. It was identified that none of the options would cost more than the current contract value. As a result of the assessment which is outlined in **Appendix 4**, option D was deemed the most cost effective option. This option would potentially enable the release of resource back into the service for further developments including an out of hours service.

3.4 Arriving at a preferred option

The table below summarises the 5 options against the 3 processes.

Option	Title	Clinical Option Appraisal	External Assessment – application of standards	Financial Appraisal
Option A	Do nothing			
Option B	Central Cochlear /distributed BAHA	✓		
Option C	Central Cochlear, Central Paediatrics BAHA Distributed adult BAHA			
Option D	Single implantable device hub for both paediatrics and adults with an outreach support model		✓	✓
Option E	1 Cochlear hub (Paediatric & adults) 1 BAHA hub (Paediatrics and adults)			

The Welsh Health Specialised Services as commissioner of the service, has responsibility to ensure the provision of high quality specialist services for the welsh population and will commission these in line with agreed service standards.

Throughout discussion, it has been made clear that the future service must:

- Accept referrals based on agreed criteria e.g. The National Institute for Health and Care Excellence (NICE)/Commissioning Policy,
- Be able to provide full Audio logical care for patients across the pathway including assessment, surgery, and device programming,
- Be able to offer access to all types of commissioned hearing implants,
- Have a functioning Multi-Disciplinary Team (MDT) where all referrals are discussed and planned for,
- Facilitate timely access to surgery,
- Facilitate rapid access to a Clinical Scientist/Physiologist when device failure is suspected,
- Provide equitable and lifelong access,
- Have clear governance processes,
- Facilitate effective liaison with relevant local services; and
- Publish data on audit and outcomes.

Having paid due regard to all three assessments, and the service standards, the only option that meets these requirements is option D.

Therefore in specifying the service WHSSC would wish to commission onward is:

A single centre for both children and adults, for the provision and maintenance of both cochlear and BAHA, ensuring that the delivery model provides a safe and sustainable hearing implant device service, which meets national standards

for the south Wales region.

The preferred option will therefore require a central hub with an outreach service. This supports the establishment of a central MDT where all referrals are discussed and planned for and where patients will be able to be offered access to all types of commissioned implants.

The option will facilitate timely and equitable access to surgery and provide life management and care for these patients offering care closer to home with the establishment of outreach clinics across the region.

3.5 Sharing the thinking with the Clinical Teams

A third workshop was held in June 2022 to share the outcome of all three processes with the members of the clinical options appraisal workshop, as well as to advise on next steps. There were differing levels of support from the clinical community regarding the preferred option, with particular concern about a centralised BAHA service. There was less concern about the centralised BAHA service. The WHSSC team articulated the reasons for option D being the preferred model that WHSSC wanted to engage and consult upon. In particular;

- Option D will ensure that patients are seen by an MDT at a hearing implantable device 'hub' that has the expertise to consider all the available treatment options in coming to an agreement with the patient on the most appropriate option for them as an individual,
- A single hearing implantable device hub will also ensure that patients are treated by clinicians and health professionals who have an adequate throughput of patients to maintain their skills, and adopt new technologies when they become available,
- Option B still maintains the very low numbers of BAHAs being done in each centre; and
- A networked model will ensure that current skills and expertise are not lost, but are built upon, and will facilitate effective liaison with relevant local services (local audiology, Speech and Language Therapist (SLT) and Teacher of the Deaf (TOD)).

It was agreed that a clinical engagement group will continue to meet throughout the engagement process to resolve any issues of concern.

3.6 Discussion with Management Group and Joint Committee

A verbal update on the process and preferred commissioning model was given to Management Group at the June meeting by way of a presentation. It was not possible to bring a full paper to Management Group at this meeting given the close proximity to workshop 3 and the Management Group meeting dates. Management Group was informed that the preferred commission option and next steps on the engagement and consultation process would be presented to Joint Committee at their July meeting.

Joint Committee received a full description of the process and the outcome at their meeting on 12th July 2022. Prior to the Joint Committee meeting Swansea Bay UHB had expressed concerns about the process. Following discussion at Joint Committee it was agreed that the Joint Committee papers would be revised to provide clarity on the process and Management Group would be asked to consider and present a view with a recommendation on the preferred option for consultation and engagement for approval at Joint Committee at their September meeting. The recommended commissioning model will be incorporated into a consultation and engagement document which will be for approval at the September Joint Committee and engagement will commence after that meeting.

3.7 Chronological Timeline for the Cochlear Implant and BAHA Hearing Implant Device Service

To aid Management Group's understanding of the process undertaken thus far the full chronology is provided below:

Name	Date	Outcome
Clinical Option Appraisal – Workshop 1	9 September 2021	Exploration of existing UK models and agreement of five options to consider at workshop 2.
Discussion at CDGB	28 September 2021	Discuss the issue raised by the clinical teams in relation to the fact that BAHA is not a technically challenging 'intervention', which therefore raised the question as to whether it should be WHSSC commissioned. The conclusion was that our aim in focusing on what is best for patients, and in line with the standards was a single implantable device hub that had the expertise to consider all the available options in coming to an agreement with the patient on the most appropriate option for them as an individual, and therefore BAHA should remain in scope as part of a 'whole system' approach. This was fed back to the clinical teams in workshop 2.
Follow up Clinical Option Appraisal - Workshop 2	30 September 2021	Stakeholders were requested to assess each delivery model against a collectively agreed set of weighted criteria using the service standards.

Name	Date	Outcome
		The outcome of the two workshops culminated in a decision that Option B scored the highest and was the preferred option.
Corporate Directors Group	8 November 2021	Received feedback from the Clinical Option Appraisal and wanted assurance that Option B met all of the standards. Agreed to commission an external assessment of all of the options to confirm which met the standards.
WHSSC letter Director of Planning to all Health Board Stakeholders and Directors of Planning	17 November 2021	Provided feedback from workshop 1 & 2. It described the next steps to undertake an external independent assessment and the application of a financial option appraisal.
Independent External Review	6 December 2021	The external assessment against the standards leads to option D being the preferred option.
Financial Appraisal	February – May 2022	All of the options could be delivered within the current allocation but the most cost efficient was Option D.
Workshop 3	16 June 2022	The workshop was held with the clinical group to share the outcome of all three aspects of the process and provide details of the timescale for delivering the engagement and consultation process. Workshop informed that the preferred commissioning model was option D as the only model that met the national standards and would therefore deliver a safe and sustainable service.
Management Group	23 June 2022	Presentation and Reported in the Managing Directors report indicating that all the necessary paperwork for sign off will be presented to Joint Committee on 12th July 2022.

Name	Date	Outcome
Corporate Directors Group Board	27 June 2022	Summarise the document for Joint Committee.
Joint Committee	12 July 2022	Management Group to review and approve the process pending sign off at JC in September 2022.

3.8 Next Steps

3.8.1 Preparation in readiness for consultation and engagement

Given that the current service remains in a status of 'temporary urgent change' an appropriate process needs to now take place to ensure the onward permanent service solution. This will be managed through the processes outlined within the '*guidance on changes to NHS services in Wales*' i.e. engagement and potential consultation.

As described above the necessary documentation and supporting timeline will be prepared in readiness for the September meeting of Joint Committee.

HB Engagement leads and the Community Health Council (CHC) have been regularly updated on the Hearing Implant work programme and the completed documentation and associated process will be shared with them for review when in a state of readiness.

3.8.2 Continued discussions with clinical teams

In sharing the proposed preferred commissioning model, clinicians expressed interest in continuing to work closely with WHSSC and as such commitment has been given to establish a clinical reference group. This will be set up at the earliest convenience to ensure a continued dialogue and shared understanding.

4.0 RECOMMENDATIONS

Members are asked to:

- **Note** the report,
- **Note** and receive assurance on the assessment process inclusive of a) clinical options appraisal, b) external review against standards and c) financial options appraisal,
- **Note** the outcome of the clinical options appraisal for the south Wales centres, the external assessment of the options and the financial appraisal,
- **Support** the preferred commissioning option as the basis of engagement/consultation; and
- **Note** that based on the Management Group's recommendation the required engagement/consultation documentation will be submitted to the September meeting of the Joint Committee.

Governance and Assurance	
Link to Strategic Objectives	
Strategic Objective(s)	Development of the Plan Choose an item. Choose an item.
Link to Integrated Commissioning Plan	Yes
Health and Care Standards	Safe Care Effective Care Timely Care
Principles of Prudent Healthcare	Care for Those with the greatest health need first Reduce inappropriate variation Choose an item.
NHS Delivery Framework Quadruple Aim	People in Wales have improved health and well-being with better prevention and self-management Choose an item. Choose an item. Choose an item.
Organisational Implications	
Quality, Safety & Patient Experience	To ensure that the delivery model will provide a safe and sustainable hearing implant device service, which meets national standards for the south Wales region.
Finance/Resource Implications	The financial assessment describes the resource requirements and the possible efficiency savings. It also identifies a need to renegotiate a new contract.
Population Health	To ensure all users of the Hearing Implant Device centre have equal access to surgery and provide life management and care for patients offering care closer to home.
Legal Implications (including equality & diversity, socio economic duty etc)	There are no known legal, equality and diversity implications.
Long Term Implications (incl WBFG Act 2015)	Ensuring patients physical and mental well-being is maximised in which choices that will benefit future health
Report History (Meeting/Date/ Summary of Outcome)	27 June 2022 - Corporate Directors Group Board meeting – Supported for inclusion on MG agenda.

Appendices	<p>Appendix 1 - South Wales Cochlear Implant and BAHA Hearing Implant Device Service Clinical Option Appraisal Outcome,</p> <p>Appendix 2 – Letter sent to workshop participants and Directors of Planning,</p> <p>Appendix 3 - South Wales Cochlear Implant and BAHA Hearing Implant Device Service – External assessment - Application of Standards; and</p> <p>Appendix 4 - South Wales Cochlear Implant and BAHA Hearing Implant Device Service Financial Appraisal</p>
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APPENDIX 1



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Services Committee (WHSSC)

SOUTH WALES COCHLEAR IMPLANT AND BAHA HEARING IMPLANT DEVICE SERVICE CLINICAL OPTION APPRAISAL OUTCOME

SITUATION

The purpose of this report is to present the outcome of the clinical option appraisal for the South Wales Cochlear Implant and BAHA Hearing Implant Device service.

BACKGROUND

Cochlear services are commissioned from two centres in South Wales, University Hospital of Wales Cardiff and Princess of Wales hospital Bridgend. During 2019, an urgent temporary service change was made as a result of the service provided from Bridgend becoming unsustainable, with all patients being moved to Cardiff. The staff associated with the service were also temporarily moved in order to support the service. At this time, there were plans to implement a formal service change, however the emergence of the pandemic resulted in a delay to the conclusion of the preparatory work and subsequent progress into formal engagement and consultation.

Following the pandemic, work has been undertaken to:

- Develop an options appraisal on the most appropriate means of delivering high quality Cochlear and BAHA services.
- Invite external assessment of the options against the service standards
- Undertake a financial appraisal of the options

This paper outlines the process and outcome of the clinical option appraisal process.

ASSESSMENT

The Clinical option appraisal took place over 2 workshops.

Workshop 1 - Exploration of existing UK models and agreement of options to consider at future workshop

Workshop 1 was intended to recommence the work which had been stopped at the outset of the pandemic, as such, it sought to re-engage clinical teams in the conversation, share models that are in place across the UK, specifically Scotland and Bristol and begin to explore the potential future options of delivery as the basis for engagement and consultation on the service.

Specifically, the group were asked to consider *'how the Cochlear Implant and BAHA service could deliver a safe and sustainable hearing implant device service for the adult and paediatric population of south Wales that meets national standards'*.

- Cochlear Implant Services for Children and Adults- Quality Standards 2018
- NHSE Clinical Commissioning Policy: Bone conducting hearing implants for hearing loss (all ages)(2016)
- NHSE Clinical Commissioning Policy: Bone anchored hearing aids(2013)

A list of options from workshop 1 were put forward as the basis of a clinical options appraisal to be undertaken at workshop 2.

OPTION	DESCRIPTION
A Do Nothing	2 Cochlear hubs for adults and children, 3 BAHA hubs for adults and children
B Central Cochlear /distributed BAHA	Single Hub (with outreach) for Cochlear 3 BAHA hubs for both adults and children
C Central Cochlear Central Paeds BAHA Distributed adult BAHA	1 Cochlear hub with cochlear outreach 1 BAHA hub (Paediatrics) 3 BAHA hubs (adult)
D Single implantable device hub	1 single centre for Cochlear and BAHA for both children and adults with an outreach support model
E 1 Cochlear hub (Children & adults) 1 BAHA hub (Children and adults)	1 single centre for BAHA (children and adults) 1 single centre for Cochlear (children and adults)

Workshop 2: Clinical options appraisal

The purpose of the second workshop was to concentrate on undertaking a clinical options appraisal. The first half of the session, set about agreeing the process, the criteria and suggested weightings in order to gain consensus with the group

on the process prior to its application. The second half afforded small group discussion on each of the options and then individual scoring against each criteria.

The criteria and associated weighting agreed for the assessment was:

Criterion	Weightings
Quality and Patient Safety	15
Achievability (Staffing, sustainability, and training)	10
Accessibility	8
Clinical Effectiveness and Efficiency	10
Acceptability	7

The clinical considerations were captured via Microsoft Teams on the day, and initial feedback on the outcome of this stage of the assessment shared. The outcome from the clinical option appraisal was as follows:

Option	Title	Score
Option A	Do nothing	402
Option B	Central Cochlear /distributed BAHA	768
Option C	Central Cochlear, Central Paediatrics BAHA Distributed adult BAHA	521
Option D	Single implantable device hub for both children and adults with an outreach support model	564
Option E	1 Cochlear hub (Children & adults) 1 BAHA hub (Children and adults)	408

The clinical option appraisal resulted in option B receiving the highest score.

APPENDIX 2

Copy of letter sent to workshop participants and Directors of Planning (copy of the SBUHB letter sent for illustration)



Your ref/eich cyf:
Our ref/ein cyf: RMS/CH/KP/KW/07/ICP
Date/dyddiad: 17th November 2021
Tel/ffôn: 01443 443443 ext 78128
Fax/ffacs: 029 2080 7854
Email/ebost: karen.preece@wales.nhs.uk

Swansea Bay University Health Board
1 Talbot Gateway
Baglan Energy Park
Baglan
Port Talbot
SA12 7BR

Dear Colleague,

RE: Cochlear Implant and BAHA Hearing Implant Device Service

Thank you for attending the recent workshops regarding the South Wales Cochlear Implant and BAHA Hearing Device services. The aim of these workshops was to gain views from the clinical community on the best way of delivering a safe and sustainable hearing implant device service for the adult and paediatric population of South Wales, which meets national standards.

This letter offers some feedback from the two workshops and offers an overview of planned next steps:

Workshops

The first workshop was designed to provide an overview of the current position, consider opportunities for strengthening the patient pathway and consider

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Chair/Cadeirydd: *Kate Eden*

Managing Director of Specialised and Tertiary Services Commissioning/Rheolwr Gyfarwyddwr Comisiynu Gwasanaethau Arbenigol a Thrydyddol: *Dr Sian Lewis*

potential options for the delivery of the service.

The second workshop focussed on undertaking a clinical options appraisal against a collectively agreed set of weighted criteria using the service standards, as the metrics for scoring the five identified options. Each participant had the opportunity to appraise and score each of the options outlined below:

	Option	Description
A	Do Nothing	2 Cochlear hubs for adults and children, 3 BAHA hubs for adults and children
B	Central Cochlear /distributed BAHA	Single Hub (with outreach) for Cochlear 3 BAHA hubs for both adults and children
C	Central Cochlear Central Paeds BAHA Distributed adult BAHA	1 Cochlear hub with cochlear outreach 1 BAHA hub (Paediatrics) 3 BAHA hubs (adult)
D	Single implantable device hub	1 single centre for Cochlear and BAHA for both children and adults with an outreach sup
E	1 Cochlear hub (Children & adults) 1 BAHA hub (Children and adults)	1 single centre for BAHA (children and adults) 1 single centre for Cochlear (children and

There was a clear preference from the clinical community on the future configuration of services.

Next Steps

Next steps include a) an independent assessment of all options against the clinical standards, and b) the application of a financial option appraisal. The output of all three processes will subsequently be presented to management group and joint committee, in order to seek a view on how they wish to proceed. It is anticipated that a period of engagement and consultation will follow this discussion.

We would like to thank all the Cochlear Implant and BAHA teams from each of the centres and Health Board Planning colleagues for their engagement and contribution to these two workshop, and look forward to working with you onward.

Yours sincerely



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Karen Preece
Director of Planning
WHSSC

Cc

Sian Harrop-Griffiths, Director of Strategy, Swansea Bay University Health Board

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Claire Harding, Assistant Director of Planning, WHSSC

James Leaves, Assistant Director of Finance, WHSSC

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APPENDIX 3



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SOUTH WALES COCHLEAR IMPLANT AND BAHA HEARING IMPLANT DEVICE SERVICE PROGRESS REPORT – EXTERNAL ASSESSMENT – APPLICATION OF STANDARDS

SITUATION

The purpose of this report is to present the outcome from the external assessment with the application of the clinical standards for the South Wales Cochlear Implant and BAHA Hearing Device service.

BACKGROUND

Cochlear services are commissioned from two centres in South Wales, University Hospital of Wales Cardiff and Princess of Wales hospital Bridgend. During 2019, an urgent temporary service change was made as a result of the service provided from Bridgend becoming unsustainable, with all patients being moved to Cardiff. The staff associated with the service were also temporarily moved in order to support the service. At this time, there were plans to implement a formal service change, however the emergence of the pandemic resulted in a delay to the conclusion of the preparatory work and subsequent progress into formal engagement and consultation.

Following the pandemic, work has been undertaken to:

- Develop an options appraisal on the most appropriate means of delivering high quality Cochlear and BAHA services.
- Invite external assessment of the options against the service standards
- Undertake a financial appraisal of the options

This paper outlines the process and outcome of the **external assessment against standards**.

ASSESSMENT

To ensure the options considered met all the clinical standards, an external assessment was undertaken by a specialist centre. The centre were asked to objectively evaluate the

same options as had been considered through the clinical option appraisal ensuring that the assessment was in line with relevant service standards as described in table 1:

The table below identifies the key standards that were considered both in the clinical option appraisal and the external assessment.

Table 1: Commissioning against standards

Accept referrals based on agreed criteria e.g. NICE/Commissioning Policy	Be able to provide full Audio logical care for patients across the pathway including assessment, surgery, and device programming
MDT where all referrals are discussed and planned for, and able to offer access to all types of commissioned hearing implants	Service has required recommended throughput required to maintain surgical (min 10 CI/surgeon/year) and clinical scientist/physiologist's skills.(centre undertakes min 15 BAHA/year)
Facilitate timely access to surgery	Facilitate rapid access to a Clinical Scientist/Physiologist when device failure is suspected(recommended that a centre should have a minimum of 3)
Provide equitable and lifelong access	Have clear governance processes
Facilitate effective liaison with relevant local services (local audiology, SLT and TOD)	Publish data on audit and outcomes

In undertaking this assessment, the external assessor arrived at the following ranking of the options:

Option	External hearing implant centre assessment
A	5
B	4
C	3
D	1
E	2

The external assessment against standards leads to option D being the preferred option.



SOUTH WALES COCHLEAR IMPLANT AND BAHA HEARING IMPLANT DEVICE SERVICE FINANCIAL APPRAISAL

SITUATION

The purpose of this report is present a financial appraisal for the South Wales Cochlear Implant and BAHA Hearing Implant Device service.

BACKGROUND

A benchmarking exercise was undertaken from three sources, the contracted value, costing returns and submitted responses from the service specification questionnaire. The different approaches produced slightly different costs for the service and these will be discussed in section 3.

This paper only addresses the current service costs but highlights the various costs of each option.

ASSESSMENT

The total budget allocated to Cochlear and BAHA service was nearly £5m, the majority of services being provided by Cardiff. (The BAHA service at Aneurin Bevan is not commissioned by Welsh Health Specialised Services) as shown in table 1.

Table 1: Table showing calculation of costs using each methodology

Provider	Service	21-22 Budget	Standard Costing	Capacity Costing (using WTE)
AB	BAHA		39,705	41,789
Cardiff	Cochlear	4,439,942	3,567,510	3,776,219
Cardiff	BAHA	486,761	461,167	596,576
SB	BAHA	63,240	45,511	63,713
	Total	4,989,943	4,113,892	4,478,297

The methods of re-costing the service give similar results but both return results below the budget. The standard costing approach uses the costing returns from each

provider to re-calculate the activity provided by the services to quantify the costs of the services. The capacity costs utilises the returns provided by each service to recalculate the pay costs based on the grade and WTE of staff employed.

The complexity of the maintenance service provision (for previous year implants) means that these have been calculated separately with a separate benchmarking exercise done.

Focusing in on the new inpatient activity for Cardiff high budget costs for new patients explain the variation between the budget and standard cost and also offer opportunities for releasing money when commissioning a preferred option. These savings could be estimated to be in the region of £250k to £500k. If these savings could be realised the funding could be used to commission the Middle Ear and the out of hours service.

The majority of activity is carried out by Cardiff, the low WTE in other centres, which would be expected reflects the lower levels of activity. In most centres, staff are not dedicated to the Cochlear and BAHA service but carry out other activity meaning any movement of services would release staff for other ENT services whilst movement of activity into a single centre would need additional funding required to cover the displaced ENT activity.

(An overhead cost of 15% has been added to parts of the standard cost methodology and the whole of the capacity cost to make the analysis comparable).

- **Theatres**

The questionnaire and the costing returns indicate that a single centre will require more than one dedicated session per week indicating that usage would be running at between 14 to 25% above a single theatre session per week.

- **Benchmarking unit costs**

Table 2 shows a comparison of unit costs obtained from the costing returns. The benchmarking indicates that a single centre, would provide a competitive service for admitted patient care.

When benchmarking the Cardiff service they incur the lowest costs for fixture of BAHAs, and Cochlear implants compared to the rest of Wales. Noting the fitting of BAHAs (figure 331) is skewed by the reference costs which is only reported as an outpatient and the cost of the implant vs. Betsi Cadwaladr is only marginally different).

There may be some further savings possible from the economies of scale and improved efficiency from greater throughput. The benchmarking of the unit costs therefore indicate the Cochlear costs at Cardiff compare favourably with the English reference costs and other Welsh providers.

Table 2: Table showing comparison of costs at each centre using reference cost data

Comparison of Admitted Patient Care (APC) Costs for each intervention					
	Fixture for Bone Anchored Hearing Aids	Fitting of Bone Anchored Hearing Aids	Unilateral Cochlear Implant	Bilateral Cochlear Implants	Cochlear Implant cost
ABUHB	✓ 2,977	⚠ 2,329			
BCUHB	✗ 3,770	✗ 4,225	✓ 22,143		✓ 16,683
C&V	✓ 3,100	✗ 3,398	✓ 20,896	✓ 39,488	✗ 16,716
SBUHB	✗ 3,974	⚠ 2,316			
Reference Costs	⚠ 3,373	✓ 331	✗ 28,006	✗ 46,271	

Key:	✓	Low cost vs. peer group	⚠	Comparable cost to peer group	✗	Higher cost than peer group
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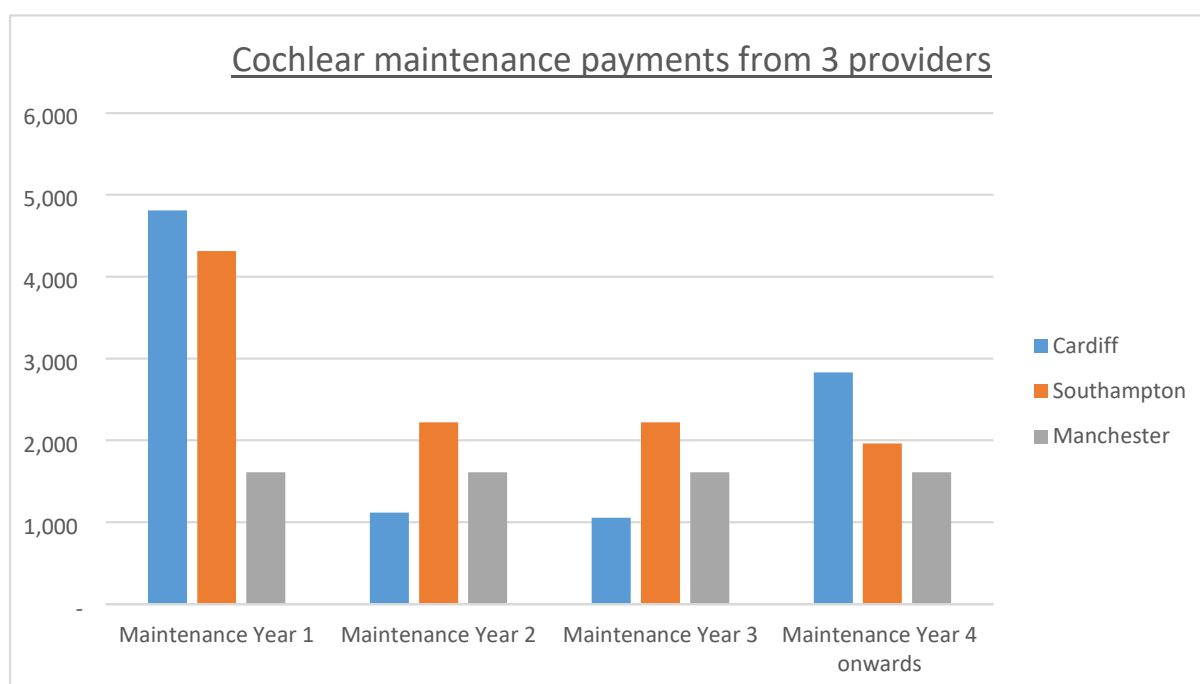
The unit cost for Cochlear Implant and BAHA in the Welsh Health Specialised Services contract are considerably higher than the Cardiff and Vale University Health Board costing returns and indicates that there are potential savings of £250k to £500k if the contract is re- negotiated.

- **Maintenance Costs**

Analysis of these costs has been carried out under a different exercise. Maintenance costs for Cochlear Implants represent over 40% of the budget for Cardiff and there is no benchmarking figures available from within Wales. Costs for maintenance have been obtained from North Wales's contract with Central Manchester and by requesting costs from Southampton University. (Southampton commented that the current service may not be providing sufficient levels of activity to meet the needs of the population in south wales).

For year one to three shown in table 4, the Cardiff costs are comparable to the other providers. However, the year four plus costs for Cardiff is above their comparators. As most of the activity is within this category, this variance has a large impact on the total costs. Using the Southampton pricelist, which is the most comprehensive of the information obtained, there appears to be possible savings available for the year 4 plus area of the contract as indicated in Appendix A. This may be an area that needs further investigation but may offer savings of £185k.

Table 3: Comparison of maintenance costs across UK providers



- **Economies of scale**

A single centre will also offer economies of scale with increased volumes in the specialist area leading to specialist staff becoming more familiar with the specialist pathway, staff being able to use their specialist skills across a larger group of patients and the realisation of greater purchasing power reducing prosthetic costs. In addition, the transfer between BAHA and Cochlear will become smoother as some patients will already be known to the service and there will be small savings from training from existing outlying centres. Costs from **Table 1** are incorporated into **Table 4**, an additional estimate of the savings from a single centre (Option D) are also included as well as the potential savings from a review of maintenance contracts and a contract review. Option E also includes some elements of the single centre savings.

Table 4 – Financial Appraisal including potential savings

Financial Appraisal of the costed Options for the Cochlear Implant and BAHA Service										
Option	Option Description	Budget 21/22	Potential Saving Minimum	Potential Saving Maximum	Revised Budget Min.	Revised Budget Max.	Option meeting all the standards	Clinical Preferred option	Independent Peer Review preferred option	Financial preferred option
		£	£	£	£	£				
		000	000	000	000	000				
A	Do Nothing Option	4,989	0	0	4,989	4,989	X			
B	Central Cochlear/distributed BAHA	4,990	435	685	4,555	4,305	X	√		
C	Central Cochlear Central Paeds BAHA/distributed Adult	4,990	435	685	4,555	4,305	X			
D	Single Implanatable device hub	4,990	535	835	4,455	4,155	√		√	√
E	1 Cochlear Hub -Paeds and Adults 1 BAHA hub Paeds and	4,990	460	710	4,530	4,280	X			

Table 4 indicates that the option meeting the Clinical standards and preferred by the Independent review: Option D; is also the most cost efficient.

Assumptions for the economies of scale:

- Centralised patient referral - reduction in appointments as some patient already known to service
- Prosthetics - continuing drop in prosthetic costs over time
- Theatres - reduction in wastage from centralisation and use of dedicated theatre
- Theatres - reduction in operation time as volume increases
- Outpatients - drop outpatient appointments and length of appointments through increased familiarity
- Staff - some specialist training limited to Centre
- Theatres - movement to day case procedures

Area	Savings
Centralised patient referral	Reduction in appointments as some patient already known
Prosthetics	Continueing drop in prosthetic costs over time
Theatres	Reduction in wastage from centraliation and use of dedicated theatre
Theatres	Reduction in operation time as volume increases
Outpatients	Drop outpatient appointments and length of appointments through increased familiarity
Staff	Some specialist training ltd. to Centre

As a result of the financial assessment **Option D** is the optimum option.



**COCHLEAR IMPLANT AND BONE CONDUCTOR HEARING IMPLANT HEARING DEVICE
SERVICES FOR CHILDREN & ADULTS IN SOUTH WALES AND SOUTH POWYS**



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7	WHAT OPTIONS DO WE HAVE TO RESPOND TO THE CHALLENGES?	18
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APPENDICES

Appendix A – Glossary of terms

1. INTRODUCTION

Many people in Wales experience hearing loss. Specialist hearing services for patients needing a Cochlear or a Bone Conductor Hearing Implant are provided from 2 Centres in South Wales, one in Cardiff and one in Bridgend. Health Boards in South Wales, South West Wales, South East Wales and South Powys have been working together to identify the best way of providing these services in the future, and would like to hear your views on these ideas. The reason we need to talk with you now is that there are temporary arrangements in place for these services, and we would like to get them to a more permanent position.

This discussion paper will answer the following questions:

- What are Cochlear implants and Bone Anchored Hearing Aids?
- Who needs a Cochlear implant or Bone Anchored Hearing Aid?
- How are services in South Wales currently organised?
- What challenges are facing the service?
- What options do we have to respond to the challenges?
- Do we have a preferred option?
- What are the advantages and disadvantages?

We would like to hear your views on the issues shared in the paper, and have developed a questionnaire that you can use to respond at Annex A. If you have feedback that you would like to comment on issues that the questionnaire does not cover, please use the commentary section at the end to share this.

We welcome views from all residents and stakeholders in South East Wales, South West Wales and South Powys who may be affected by the contents of this paper. An Equality Impact Assessment screening has been developed for this service, which the responses to this engagement will further inform. Both will be published as part of the outcome of the engagement process.

Due to the nature of the service, we recognise that this document will have some medical terms within it that may not be familiar to all. There is a description of these words in Annex 2.

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2. WHAT ARE COCHLEAR IMPLANTS AND BONE CONDUCTOR HEARING IMPLANTS?

Hearing loss affects over 10 million people across the United Kingdom. It can lead to significant health and mental health issues¹. It is a very common condition affecting around one in seven of the population. As we get older, the chance of us having hearing loss increases.

Many people with hearing loss wear a hearing aid which make sounds louder in the ear. Not everybody is able to wear a hearing aid because of the shape or size of their ear, or some other medical reason. Patients who are unable to wear a hearing aid may be considered for a cochlear implant or bone anchored hearing aid.

What is a Cochlear Implant?	What is a Bone Conductor Hearing Implant?
A cochlear implant stimulates the nerves in the inner ear. It is implanted in the ear	A Bone Conductor Hearing Implant(BCHI) is a hearing aid which uses bone conduction to help sound get to the inner ear.

Specialist services that support people needing cochlear and or BCHI aids aim to:

- Improve speech and quality of life.
- Promote normal development of hearing
- Provide a remediation service for paediatric rehabilitation – this could be through direct input or an advisory service.
- Provide a high quality, family focused cochlear implant and BCHI programme.

¹ [Overview | Cochlear implants for children and adults with severe to profound deafness | Guidance | NICE](#)

- Promote understanding and the use of spoken language in children
- Provide remote rehabilitation and care to ensure patients get the maximum benefit from their device.
- Use of auditory devices to restore hearing functions and enhance the listener's quality of life to optimise the patients experience.

DRAFT

3. WHO NEEDS THESE SERVICES?

What do we know about hearing loss in Wales?



There are approximately **613,000** people over the age of 16 with severe/profound deafness in England and Wales.

Around **370** children in England and **20** children in Wales are born with permanent severe/profound deafness each year. Around **90%** of these children live with hearing parents. About 1 in every 1,000 children is severely or profoundly deaf at 3 years old. It is 2 in every 1'000 between the ages of 9 – 16.

There are more women than men with hearing loss, which is because women live longer than men. Some ethnic groups may also have higher rates of hearing loss.

Patients that doctors believe could be helped by a hearing implant, are sent to a specialist hearing centre to be seen by a team of clinical staff (a multi-disciplinary team) who will assess whether a patient should have a hearing implant. Not all patients will be suitable for a hearing implant.

It is really important that children who have hearing loss are identified and seen early so that they can learn to speak well, take part in school and learning, make friends and have good conversations.

Patients who receive a cochlear implant or BCHI hearing device may have:

- A chronic ear disease
- Deafness in one or both ears
- Ear canal problems
- Malformations of or absent ear structures

4. HOW ARE COCHLEAR IMPLANT AND BCHI SERVICES CURRENTLY ORGANISED IN SOUTH WALES?

National Context

The Welsh Health Specialised Services Committee is responsible for the commissioning (buying and monitoring) of Cochlear Implant and BCHI Hearing Implant Device services for Welsh residents.

There are two specialist centres for Cochlear services:



- one at the University Hospital of Wales, Cardiff and Vale University Health Board and;



- one at the Princess of Wales Hospital, Cwm Taf Morgannwg University Health Board

These centres work together and are recognised as the South Wales Cochlear Implant service for children and adults in South Wales and South Powys.

There are three centres delivering the Bone Conductor Hearing Implant service and these are located at:



**The Royal Gwent
Hospital in
Newport**



**Neath Port Talbot
Hospital**



**Cardiff & Vale
University
Health Board**

Services from Cardiff & Vale and Neath Port Talbot are bought and monitored (commissioned) by WHSSC. The service at Aneurin Bevan University Health Board is not

People from across South Wales and South Powys are referred to one of the two centres.

People living in the following areas are referred to (sent to and seen at) the Princess of Wales Hospital Bridgend within the Cwm Taf Morgannwg University Health Board area:

Carmarthenshire
Ceredigion
Pembrokeshire
Pembrokeshire
Neath
Bridgend
small number of south Powys patients

People living in the following areas are referred to (sent to and seen at) the University Hospital of Wales, Cardiff:

Cardiff and Vale
Gwent
Merthyr Tydfil

Rhondda Cynon Valley
Taff Ely
small number of south Powys patients

The North Wales Cochlear Implant Programme and BCHI service is delivered in Glan Clwyd Hospital, Betsi Cadwaladr University Health Board, with the children's cochlear implant service being in Central Manchester University Hospitals NHS Foundation Trust. Services for people living in North Wales and North Powys are not included in this engagement.

To deliver these services the Hearing Device Implant Centre must provide the following²:

- All patient areas should be appropriate to the needs of a hard hearing population and take into account the needs of families and young children.
- A specialist hearing implant device centre should include the full range of staff to deliver it in line with the standards.

Guidance suggests the following roles:

- Otorhinolaryngologist/ENT surgeon,
- Audiological Scientists,
- Hearing Therapist,
- Speech & Language Therapist,
- Clinical Psychologist

In addition for children:

- Paediatric Anaesthetist,
- Teacher of the Deaf
- Speech & Language Therapist,
- Clinical Psychologists,
- Specialist Radiologists
- Specialist Nurses

² <https://www.bciq.org.uk/wp-content/uploads/2021/03/QS-update-2018-WORD-final-v2.pdf>

- The hearing implant team must be suitably qualified and registered with the appropriate professional bodies. All members must continue to maintain continual professional development, and all will have training in deaf awareness and knowledge of the full range of hearing implants.
- Hearing implant services must have access to appropriately calibrated and up to date equipment and facilities to enable appropriate assessments to take place.
- Audiological testing will need to be undertaken in sound treated rooms where the ambient noise levels are compliant with the BBS EN ISO 8253-1 1998 standard.
- Day case
- Operating Theatres
- Outreach clinics to provide care closer to the patients home
- Offer remote programming for cochlear implants

5. HOW DOES THE SERVICE PERFORM?

There are three pieces of information that are reported by the service, these are:

- Referrals – the number of adults and children who need the specialist service and are referred by their doctor
- Waiting times – length of time adults and children have to wait in weeks or days to be seen for treatment
- Activity – number of adults and children who receive treatment

Table 1 shows the number of adults and children who are referred to the Cochlear and Bone Conduction Hearing Implant (BCHI) service over the last four years. The BCHI information is shown as an average figure.

Table 1: Referrals

Cochlear Implants Referrals	2017/18	2018/19	2019/20	2020/21
Adults	56	57	82	31
Paediatrics	20	17	31	12
Average Number BCHI Referrals				
Adults	42	42	42	42
Paediatrics	2.5	2.5	2.5	2.5

The next table shows the how long adults and children are likely to wait to receive treatment for a cochlear or bone conduction hearing implant during 2019/20. The Cardiff and Vale University Health Board is the only centre in south wales that has a cochlear implant service.

Table 2: Waiting Times 2019/20

Cochlear Implants Waiting time	Cardiff and Vale University Health Board	Swansea Bay University Health Board	Aneurin Bevan University Health Board
New adult patients	8 weeks	Not applicable	Not applicable
New paediatrics patients	4 weeks	Not applicable	Not applicable
BCHI Waiting Time			
New BCHI patients	2-3 weeks	12 weeks	24 weeks

Table 3 shows the number of adults and children that were treated in the last four years.

The numbers were much lower in 2020/21 due to the covid 19 pandemic.

Activity

Cochlear Implant Activity	2017/18	2018/19	2019/20	2020/21
Adults	14	28	32	30
Paediatrics	16	15	17	16
BCHI Activity				
Adults	25	21	18	4
Paediatrics	0	0	0	0

Outcome Measures for Cochlear Implants

The service are required to take account of national standards to ensure that treatment is provided in the best possible way. Patients are asked to complete a number of questionnaires asking about their hearing loss, how it is affecting them and whether the hearing implant has improved their hearing and general quality of life. These are called Patient reported outcome measures (PROMS).

There are other tests that can be used to measure how well a person can hear words or words in sentences, without lip reading. These tests are used to see if the adult or child is suitable for a cochlear implant. This is known as a speech test measurement and is performed before surgery but again after surgery to measure the change and whether there has been an improvement in the quality of their hearing.

For those adults or children who have been assessed and may be suitable for a bone conduction hearing implant, speech tests are not usually used. The measure is more around reduction in pain, ear infections, ear mould allergies or how well the implant fits compared to a general acoustic hearing aid.

6. WHAT ARE THE CHALLENGES FACING COCHLEAR IMPLANT AND BCHI HEARING DEVICE SERVICES IN SOUTH WALES?

Services face a number of current challenges which are outlined here:

- **Workforce challenges**

During 2019, it was established that the service provided from the Princess of Wales hospital in Bridgend service was facing workforce challenges and became unsustainable due to the immediate withdrawal of the Principal Clinical Scientist from the service. The Bridgend service was without Audiology support and were not able to meet some of the quality indicators to achieve the minimum standards as recommended by the British Cochlear Implant Group due the staffing shortage.

In line with the guidance on '*Changes to NHS services in Wales*', arrangements were made for the temporary transfer of Cochlear surgery services from Cwm Taf Morgannwg to Cardiff and Vale University Health Board. The change means that patients who would have gone to Princess of Wales Hospital Bridgend for surgery and out-patient appointments would temporarily be seen at the University Hospital of Wales Cardiff. Staff from the Bridgend service were also temporarily transferred to support the provision of the service in Cardiff, enabling a level of continuity to patients previously being seen in the Princess of Wales hospital.

- **Meeting Quality Standards**

To deliver services, specialist hearing centres should meet the 'British Cochlear Implant Group Quality Standards'. The key standards are set out overleaf:

Accept referrals based on agreed criteria e.g. NICE/Commissioning Policy	Be able to provide full Audiological care for patients across the pathway including assessment, surgery, and device programming
MDT where all referrals are discussed and planned for, and able to offer access to all types of commissioned hearing implants	Service has required recommended throughput required to maintain surgical (min 10 CI/surgeon/yr) and clinical scientist/physiologist's skills.(centre undertakes min 15 BAHA/yr)
Facilitate timely access to surgery	Facilitate rapid access to a Clinical Scientist/Physiologist when device failure is suspected(recommended that a centre should have a minimum of 3)
Provide equitable and life long access	Have clear governance processes
Facilitate effective liaison with relevant local services (local audiology, SLT and TOD)	Publish data on audit and outcomes

The British Cochlear Implant standards recommends:

- that a Cochlear Implant Centre should have a minimum of two experienced ear surgeons with an annual surgical activity level of 10 per year per surgeon in order to maintain high levels of skill and experience.

Recommendations on standards for BCHI services comes from a consensus statement of experts , which states:

- that BCHI fitting should take place in a specialist centre performing at least 15 procedures per year.³

Not all units are able to achieve the quality standards that are set out in the British Cochlear Implant Group guidelines ⁴ and NHS England Clinical Commissioning Policy for Bone Anchored Hearing.⁵

- **Services spread across the South Wales region**

Services are widely spread across the region. Some of the centres have single handed specialist staff, which means that there is no cross

³ <https://www.england.nhs.uk/wp-content/uploads/2013/04/d09-p-a.pdf>

⁴ <https://www.bcig.org.uk/bcig-constitution-quality-standard/>

⁵ <https://www.england.nhs.uk/wp-content/uploads/2013/04/d09-p-a.pdf>

cover when people are on leave. There is no arrangement in place for skilled staff to rotate into these posts and clinical staff are often also working in audiology and Ear Nose and Throat services. There are challenges in recruiting staff to roles and in some centres there has been a lack of opportunity for development due to the gaps in the workforce.

- **Waiting Times**

Waiting times across the region vary from centre to centre and there is no central Multi-Disciplinary Team provision, which means that not all patients have the opportunity to be considered for all types of hearing implant devices.

Impact of the challenges

All of the issues above have led to the suggestion of a centralised service in order to realise economies of scale and seek to address the challenges outlined.

7. WHAT OPTIONS HAVE WE CONSIDERED TO RESPOND TO THE CHALLENGES?

Our aim is to have a Cochlear Implant and BCHI Hearing Implant Device Service that:

- can deliver a safe and sustainable hearing implant device service for the adult and paediatric population of South Wales
- has equitable access
- meets national standards
- has staff in the right place with the right specialist skills
- facilitates timely access to surgery

To consider the best option, 3 pieces of work have been done:

- a) a clinical option appraisal
- b) an external assessment of the options and how they would deliver against relevant service standards
- c) a financial option appraisal

Underpinning all 3 were the British Cochlear Implant Group guidelines⁶ and the NHS England BCHI Commissioning document.

Below is a summary of the work:

- **Clinical Option Appraisal**

A series of workshops with clinical teams were held between September 2021 and June 2022 with the aim of discussing the best way of delivering a safe and sustainable hearing implant device service for the adult and paediatric population of South Wales that meets national standards.

The group considered 5 options for the delivery of specialist hearing services in the future and scored them against the following criteria:

- Quality and Patient Safety
- Achievability (Staffing, sustainability, and training)
- Accessibility
- Clinical Effectiveness and Efficiency
- Acceptability

⁶ <https://www.bciq.org.uk/>

The options considered were:

	Option	Description
A	Do Nothing	2 Cochlear hubs for adults and children, 3 BCHI hubs for adults and children
B	Central Cochlear/distributed BCHI	Single Hub (with outreach) for Cochlear 3 BCHI hubs for both adults and children
C	Central Cochlear Central Paediatrics BCHI Distributed adult BCHI	1 Cochlear hub with cochlear outreach 1 BCHI hub (Paediatrics) 3 BCHI hubs (adult)
D	Single implantable device hub	1 single centre for Cochlear and BCHI for both children and adults with an outreach support model
E	1 Cochlear hub (Children & adults) 1 BCHI hub (Children and adults)	1 single centre for BCHI (children and adults) 1 single centre for Cochlear (children and adults)

The clinical team expressed a preference for Option B.

- **External Assessment**

To consider the options against the National standards, a specialist hearing centre from within NHS England was asked to objectively review the options.

In undertaking this assessment, the external assessor arrived at the following ranking of the options:

Option	External hearing implant centre assessment
A	5
B	4
C	3
D	1
E	2

The outcome of the external assessment against the standards leads to option D being the preferred option.

- **Financial Appraisal**

Finally, each of the options was reviewed financially. It was concluded that none of the options would cost more than the money that is currently invested in the service, in fact that through consolidating the services that there was an opportunity to release money for investment in an out of hours service, and other service developments.

The outcome of the financial appraisal identified that Option D, a single implantable device hub for both children and adults with an outreach support model was the most cost efficient option.

In summary of the outcome of the 3 pieces of work:

Option	Title	Clinical Option Appraisal	External Assessment against of standards	Financial Appraisal
Option A	Do nothing			
Option B	Central Cochlear /distributed BCHI	√		
Option C	Central Cochlear, Central Paediatrics BCHI Distributed adult BCHI			
Option D	Single implantable device hub for both children and adults with an outreach support model		√	√
Option E	1 Cochlear hub (Children & adults) 1 BCHI hub (Children and adults)			

8. DO WE HAVE A PREFERRED OPTION?

Welsh Health Specialised Services as commissioner of the service has the responsibility to consider the most appropriate means of commissioning the service onward.

There are a number of key messages taken from the national standards that the service must have.

A service must:

- Accept referrals based on agreed criteria e.g. NICE/Commissioning Policy,
- Be able to provide full Audiological care for patients across the pathway including assessment, surgery, and device programming,
- Be able to offer access to all types of commissioned hearing implants,
- Have a functioning MDT where all referrals are discussed and planned for,
- Facilitate timely access to surgery,
- Facilitate rapid access to a Clinical Scientist/Physiologist when device failure is suspected,
- Provide equitable and lifelong access,
- Have clear governance processes,
- Facilitate effective liaison with relevant local services; and
- Publish data on audit and outcomes.

Having considered all three assessments against the national standards the only option that meets these requirements is **Option D, a single implantable device hub for both children and adults with an outreach support model. This is the model that WHSSC would like to commission onward.**

9. IMPACT OF THE CHANGE

The suggestion above will enable the safe and sustainable delivery of services for patients requiring an implantable device which will include assessment, surgery and device programming. It will also include the full range of staff required to support the service, and see sufficient numbers of patients for the clinical team to maintain a high level of skill.

The service would:

- support rapid access to a Clinical Scientist/Physiologist when device failure is suspected at all centres and provide equitable and lifelong access.
- ensure equity of access for all patients (i.e. all patients having the same options open to them, and considered for them).
- support a critical mass of patients required for the adoption of new technological advances.
- provide remote digital programming and outreach clinics in the local health boards to improve access to services.

What is the Impact?

- Some patients and families may need to travel further distance to receive the service.
- Patients would be treated at a centre carrying out higher numbers of the procedures, which is linked to improved outcomes
- There is the opportunity to use money more efficiently potential opportunity to reinvest in new developments for the service to have an improved service comparable to other regional hearing implant device centres

10. HOW CAN YOU CONTRIBUTE: ENGAGEMENT AND CONSULTATION

This is the start of our conversation with you about the Cochlear Implant and BCHI Hearing Implant Device service in South Wales and South Powys. We would like to you to share your views about what you have read.

Some of the things we would be interested to learn from you are whether:

- you have an understanding of the Cochlear Implant and BCHI Hearing Implant Device service as a result of reading this document
- you have a better awareness of how the services are currently provided as a result of reading this document
- the challenges facing the service and the options that have been considered for the future delivery of the services are clear
- your views on the preferred model

Next Steps

- When the engagement exercise has ended, all information received will be shared with the individual Health Boards and Board of Community Health Councils. We will also make available a report that outlines a summary of what has been received. We will consider all of your comments and decide take any necessary mitigating actions as a result. We will also update the Equalities Impact Assessment.

On discussing the outcome with Community Health Council, a further period of consultation may be needed. If this is required we will once again invite your views.

A questionnaire is available at the end of this document to aid your response. It should be returned to:

Cochlear and BCHI engagement
Welsh Health Specialised Services Committee
Unit G1 Main Avenue

Treforest
Pontypridd
CF37 5YL

Or alternately (insert WHSSC generic e-mail)

We would welcome your feedback by date.....



APPENDIX 1– GLOSSARY OF TERMS

Audiology	The branch of science and medicine concerned with the sense of hearing.
Cochlear Implant System	A cochlear implant is an implanted electronic hearing device designed to produce useful hearing sensations to a person with severe to profound nerve deafness by electrically stimulating nerves inside the inner ear.
Congenital	Existing from Birth or before
Otorhinolaryngologist/ENT surg	A doctor who studies or treats diseases of the ear, nose, and throat.
Audiological scientists	A clinical scientist that specialises in the diagnosis, analysis and treatment of human auditory disorders such as hearing, tinnitus and audio balance deficiencies.
Hearing therapist	A Hearing Therapist offers counselling to help with hearing difficulties
Speech and Language Therapist	A Speech and language therapists provide life-changing treatment, support and care for children and adults who have difficulties with communication, eating, drinking and swallowing.
Clinical Psychologist for children	Clinical child psychologists work with children by assessing, diagnosing and treating children and adolescents with psychological or developmental disorders, and they conduct academic and scientific research
Paediatric Anaesthetist	Pediatric anaesthesiologists are responsible for the general anesthesia, sedation, and pain management needs of infants and children
Teacher of the Deaf (TOD)	Teachers of the Deaf (also known as ToDs or teachers of the hearing impaired) are qualified teachers who provide support to deaf children, their parents and family, and to other professionals who are involved with a child's education.
Specialist Radiologists	Specialised Radiologists are medical doctors that specialise in diagnosing and treating injuries and diseases using medical imaging (radiology) procedures (exams/tests) such as X-rays, computed tomography (CT), magnetic resonance imaging (MRI), nuclear medicine, positron emission tomography (PET) and ultrasound.

Specialist Nurses	Specialist nurses are dedicated to a particular area of nursing; caring for patients suffering from long-term conditions and diseases
NICE	National Institute of Clinical Excellence
MDT	Multi-disciplinary Team
SLT	Speech and language therapy

DRAFT

PROPOSED CHANGES TO THE SOUTH WALES COCHLEAR IMPLANT AND BONE CONDUCTION HEARING IMPLANT (BCHI) DEVICE SERVICE EQUALITY IMPACT ASSESSMENT (EIA)

1. INTRODUCTION

In order to demonstrate that a public sector body has given due regard to the general duty, public sector bodies in Wales are required under the Welsh Public Sector Equality Duties to conduct an equality impact assessment (EIA) of their policies and service developments in order to assess the potential impact(s) upon people with protected characteristics.

This purpose of this document is to set out the narrative and findings of the equality impact assessment (EIA) of proposed changes to the Cochlear Implant and BCHI Hearing Implant Device Services in South Wales.

Equality is about making sure people are treated fairly. It is not about treating 'everyone the same', but recognising that everyone's needs are met in different ways. As part of this duty, public sector bodies in Wales are required to publish an assessment of impact in order to be transparent and accountable i.e. their consideration of the effects that their decisions, policies or services have on people on the basis of their gender, race, disability, sexual orientation, religion or belief, and age, to include gender re-assignment, pregnancy and maternity, marriage and civil partnership issues. These are classed as 'protected characteristics', it is relevant because people from within protected groups are more likely to experience it. Such high levels of deprivation in our local community mean that 36% of the Cwm Taf population live in areas which are among the most deprived 20% in Wales.

In addition we recognise that Wales is a country with two official languages: Welsh and English. The importance of bilingual healthcare for all patients in Wales is fundamental and is particularly important for four key groups - people with mental health problems; those with learning disabilities; older people and young children. Research has shown these groups cannot be treated effectively except in their first language. Our consideration of equality takes account of this.

Hearing loss affects over 10 million people across the United Kingdom which makes it the second most common disability in the UK. It can lead to significant health and mental health issues. It is a very common condition affecting approximately one in seven of the population, with a steeply increasing incidence with age.

Background

The intention to consolidate the cochlear implant service in South Wales has been discussed for some time. The reasons cited were the close proximity of the two providers, the disjointed delivery of activity and infrastructure.

During 2019, an urgent temporary service change was made as a result of the service provided from Bridgend becoming unsustainable, with all patients being moved to Cardiff. The staff associated with the service were also temporarily moved in order to support the service.

At this time, there were plans to implement a formal service change, however the emergence of the pandemic resulted in a delay to the conclusion of the preparatory work and subsequent progress into formal engagement and consultation.

Whilst the urgent temporary change related to the provision of Cochlear Implant services, the original discussion related to both Cochlear and BCHI. The scope of the project was revised to include both Cochlear, BCHI, adult and children services.

The EIA will help with answering the following questions:

- Do different groups have different needs, experiences, issues and priorities in relation to the proposed service change?
- Will the proposed service change promote equality?
- Will the proposed service change affect different groups differently?
- Is there evidence of negative impact and what alternatives are available?

2. CURRENT SERVICE PROVISION

Cochlear Implant services are commissioned from two centres in South Wales:

- University Hospital of Wales Cardiff and Vale University Health Board
- Princess of Wales Hospital, Bridgend, Cwm Taf Morgannwg University Health Board

The BCHI Hearing Implant Services are located at three sites:

- Neath Port Talbot Hospital, Swansea Bay University Health Board
- University Hospital of Wales, Cardiff and Vale University Health Board
- Royal Gwent Hospital, Aneurin Bevan University Health Board.

3. PROPOSED SERVICE PROVISION

Following the pandemic, work has been undertaken to:

- Develop an options appraisal on the future commissioning of the service, with the scope of that consideration also including the provision of BCHI Hearing Implant Devices.
- An external assessment of the options against the service standards
- A financial appraisal of the options

A Clinical option appraisal workshop took place in September 2021, with invites extended to clinical teams and planning colleagues from Health Boards affected by any proposed change. Five options were presented for consideration and participants had the opportunity to consider and influence both criteria and weightings, before being asked to score each option against the weighted criteria.

The options were:

	OPTION	DESCRIPTION
A	Do nothing	2 Cochlear hubs for adults and children 3 BCHI hubs for adult and children
B	Central Cochlear Distributed BCHI	Single hub (with outreach) for Cochlear 3 x BCHI hubs for both adults and children
C	Central Cochlear, Central Paeds BCHI, distributed Adult BCHI	1 x Cochlear hub with Cochlear outreach 1 x BCHI hub (paediatrics) 1 x BCHI hub (adult)
D	Single implantable device hub	1 x single centre for Cochlear and BCHI for both children and adults with an outreach support model
E	1 cochlear hub (Children and adults) 1 BCHI hub (Children and adults)	1 x single centre for BCHI (children and adults) 1 x single centre for Cochlear (Children and adults)

Following application of weighted criteria by each person present, the preferred option from the clinical options appraisal was Option B.

Single hub (with outreach) for Cochlear 3 x BCHI hubs for both adults and children

In order to assess the options against relevant service standards, an external assessment was undertaken by members of the Bristol Specialist Hearing Centre. The same options and criteria as those used in the clinical option appraisal were used. The following standards were used as a framework for assessment:

Accept referrals based on agreed criteria e.g. NICE/Commissioning Policy	Be able to provide full Audio logical care for patients across the pathway including assessment, surgery, and device programming
MDT where all referrals are discussed and planned for, and able to offer access to all types of commissioned hearing implants	Service has required recommended throughput required to maintain surgical (min 10 CI/surgeon/year) and clinical scientist/physiologist's skills.(centre undertakes min 15 BCHI/year)

Facilitate timely access to surgery	Facilitate rapid access to a Clinical Scientist/Physiologist when device failure is suspected(recommended that a centre should have a minimum of 3)
Provide equitable and lifelong access	Have clear governance processes
Facilitate effective liaison with relevant local services (local audiology, Speech and Language Therapist (SLT) and Teacher of the Deaf (TOD)	Publish data on audit and outcomes

Through external assessment of the options against the standards, the only option considered to meet all standards was option D.

4. FINANCIAL ASSESSMENT

The budget for the Cochlear and BCHI Hearing Implant service is almost £5m, with the majority of investment going to Cardiff and Vale University Health Board. A financial assessment of each of the options was undertaken using contract values, costing returns and service proformas, It was identified that none of the options would cost more than the current contract value.

5. ARRIVING AT A PREFERRED OPTION

The table below summarises the 5 options against the 3 processes enabled.

Option	Title	Clinical Option Appraisal	External Assessment – application of standards	Financial Appraisal
Option A	Do nothing			
Option B	Central Cochlear /distributed BCHI	✓		
Option C	Central Cochlear, Central Paediatrics BCHI Distributed adult BCHI			
Option D	Single implantable device hub for both paediatrics and adults with an outreach support model		✓	✓
Option E	1 Cochlear hub (Paediatric & adults) 1 BCHI hub (Paediatrics and adults)			

Welsh Health Specialised Services as commissioner of the service, has responsibility to ensure the provision of high quality specialist services for the welsh population and will commission these in line with agreed service

standards. Throughout discussion, it has been made clear that the future service must:

- Accept referrals based on agreed criteria e.g. The National Institute for Health and Care Excellence (NICE)/Commissioning Policy,
- Be able to provide full Audio logical care for patients across the pathway including assessment, surgery, and device programming,
- Be able to offer access to all types of commissioned hearing implants,
- Have a functioning Multi-Disciplinary Team (MDT) where all referrals are discussed and planned for,
- Facilitate timely access to surgery,
- Facilitate rapid access to a Clinical Scientist/Physiologist when device failure is suspected,
- Provide equitable and lifelong access,
- Have clear governance processes,
- Facilitate effective liaison with relevant local services; and
- Publish data on audit and outcomes.

6. THE PREFERRED OPTION

Having paid due regard to all three assessments, and the service standards, the only option that meets these requirement is option D which is;

A single implantable Hub with outreach model with a central Multi-Disciplinary Team provision

- A single centre for both children and adults, for the provision and maintenance of both cochlear and BCHI, ensuring that the delivery model provides a safe and sustainable hearing implant device service, which meets national standards for the south Wales region.
- The preferred option will therefore require a central hub with an outreach service. This supports the establishment of a central MDT where all referrals are discussed and planned for and where patients will be able to be offered access to all types of commissioned implants.
- The option will facilitate timely and equitable access to surgery and provide life management and care for these patients offering care closer to home with the establishment of outreach clinics across the region.

As well as the perceived benefits outlined above, the other key implications of the proposed relocation that are likely to have an impact on patients and staff are:

How will it be delivered

Central Hub

A decision has yet to be made on where the single site will be located in south Wales but there are a number of considerations:

All patient areas should be able to meet the needs of a hard of hearing population and the needs of families and young children

There should be a full range of specialist staff to provide the service to meet the national standards

There is a need to have other services at the same site for example day case, operating theatres

The centre must provide a central multi-disciplinary team where all referrals are discussed and planned for

Outreach Services

The location of outreach services has not been agreed but here are some suggested centres:

- Neath Port Talbot, Swansea Bay University Health Board
- A location in north Cwm Taf Morgannwg University Health Board
- A location in Aneurin Bevan University Health Board
- University Hospital of Wales, Cardiff and Vale University Health Board

Patient parking

This is available at all sites. There are no car parking charges within Wales's hospital sites.

Staff parking

This is available at all sites. Members of staff who wish to park on site may need to apply for a permit. A permit does not guarantee them a parking space on site. Staff must park in designated staff car parks.

Healthcare Travel Costs Scheme

Under this scheme, patients on low incomes or receiving specific qualifying benefits or allowances are reimbursed in full or in part for costs incurred in travelling to receive NHS services provided in a hospital. This includes:

- Income support benefit
- Income based job seekers allowance

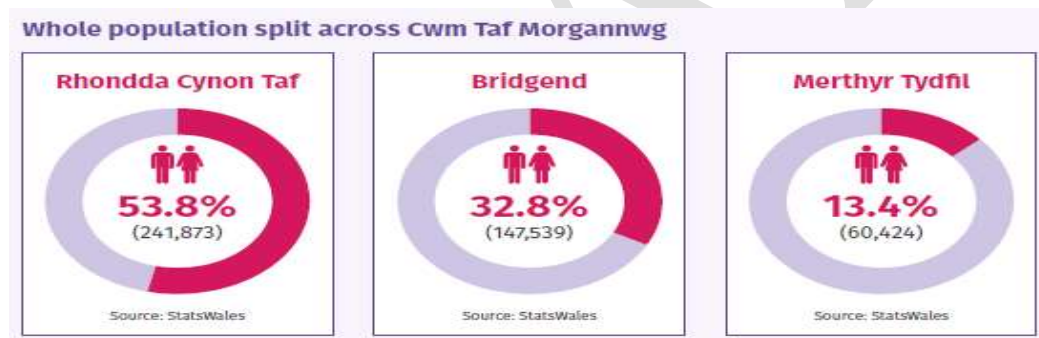
- Working tax credit or child tax credit
- Or hold a HC2 or HC3

7. THE DEMOGRAPHIC PROFILE

The Wales average life expectancy is 78.3 years for men, 82.3 for women with healthy life expectancy 65.3 years for men, 66.7 for women. For Cwm Taf Morgannwg, the life expectancy and healthy life expectancy for both men and women is lower than the Wales average. The gap in life expectancy and healthy life expectancy in Cwm Taf is lower than Wales and there are great inequalities in outcomes for the poorest compared to the most affluent.

Cwm Taf overall had statistically highlighted higher levels of mental illness, respiratory illness, hypertension, arthritis and diabetes mellitus in the combined 2012-2013 Welsh Health Survey compared with other areas in Wales.

According to Action on Hearing Loss in Wales, there are around 575,500 deaf and hard of hearing people in Wales. Cwm Taf Morgannwg is made up of three local authority areas: Merthyr Tydfil, Rhondda Cynon Taf and Bridgend. There are 449,836 people living in Cwm Taf Morgannwg. ¹



Cwm Taf has an ageing population, recognised health inequality (Inverse Care Law) and high levels of deprivation. There is an associated lower life expectancy (8 less years for males and 6 less years for females between the poorest and most affluent areas within the Cwm Taf community), shorter good health (the lowest in Wales) and high incidence of multiple morbidities. The population is growing and there is low employment and low levels of academic achievement.

Taff Ely is an area of significant contrast, with pockets of both affluence and high deprivation. Compared to the rest of the Cwm Taf UHB area, Taff Ely appears relatively affluent with 26.8% of its population living in the least

¹ https://www.ctmregionalpartnershipboard.co.uk/wp-content/uploads/2022/05/CTM-Regional-Partnership-Board-Population-Needs-Assessment-Summary_e5.pdf

deprived areas of Wales. However, 38.8% of its population live in the most deprived or next most deprived areas. Particularly relevant is the identification of Tylorstown (Rhondda), Caerau (Bridgend), Penrhiwceiber (Rhondda Cynon Taf) and Penydarran (Merthyr Tydfil) as areas of greatest deprivation in Wales (ranked 4th, 5th, 6th and 7th respectively).² This level of deprivation in the area brings with it associated high rates of mental health issues, long term disability/morbidity, and chronic illness from the legacy of heavy industry particularly mining, and benefits uptake.

8. UNDERSTANDING THE IMPACT ON PROTECTED CHARACTERISTICS

The proposal to locate a single implantable device hub for both paediatrics and adults with an outreach support model will therefore affect patients living in the local health board regions of Cwm Taf Morgannwg, Aneurin Bevan, Cardiff and Vale, Hywel Dda, Swansea Bay and parts of Powys.

Gender/Sex

In the Cwm Taf area as a whole there are a very slightly higher proportion of female residents than male, and this is broadly consistent with the rest of Wales.

The gender split for the area affected by service change mirrors very closely the gender split for Wales as a whole; approximately a 50:50 split with slightly more females (51%) than males (49%).

Region	Males	Females	Total (%)	Total
Aneurin Bevan UHB	49.0%	51.0%	100.0%	576,754
Caerphilly	49.0%	51.0%	100.0%	178,806
Blaenau Gwent	49.2%	50.8%	100.0%	69,814
Torfaen	48.7%	51.3%	100.0%	91,075
Monmouthshire	49.2%	50.8%	100.0%	91,323
Newport	49.0%	51.0%	100.0%	145,736
Cardiff and Vale UHB	49.0%	51.0%	100.0%	472,426
Vale of Glamorgan	48.7%	51.3%	100.0%	126,336
Cardiff	49.1%	50.9%	100.0%	346,090
Cwm Taf UHB	48.9%	51.1%	100.0%	293,212
Rhondda Cynon Taf	48.9%	51.1%	100.0%	234,410
Merthyr Tydfil	49.0%	51.0%	100.0%	58,802
Powys THB	49.4%	50.6%	100.0%	132,976
South Powys*	49.4%	50.6%	100.0%	66,488
Area affected*	49.0%	51.0%	100.0%	1,408,880

² <https://gov.wales/sites/default/files/statistics-and-research/2020-06/welsh-index-multiple-deprivation-2019-results-report.pdf>

Wales 49.1% 50.9% 100.0% 3,063,456

Car travel is the most common means of transport for both men and women from all age groups, including children. However, children make more walking trips than adults. For all age groups, men drive further than women on average. According to the Department of Transport's Road Use Statistics 2016, nationally men are more likely than women to be car drivers, with 80% of men compared to 67% of women holding a driving licence in 2014.

It is therefore assumed that older female patients are most likely to be impacted by the change of location to the University Hospital of Wales due to their likely reliance on public transport. The evidence of a gender difference in access to transport is a relevant consideration in relation to this service change since a single centre would mean some patients and families travelling further than they would otherwise need to, however some patients will be travelling less, based on the current available evidence, no impact is anticipated on this protected characteristic group but may need further detail following the engagement process.

Age

Approximately 370 children in England and 20 children in Wales are born with permanent severe to profound deafness each year. About 1 in every 1000 children is severely or profoundly deaf at 3 years old. This rises to 2 in every 1000 children aged 9 to 16 years. About half the incidence of childhood deafness is attributed to genetic causes, although approximately 90% of deaf children come from families with no direct experience of deafness. Causes of severe to profound hearing loss in children also include conditions such as meningitis and viral infection of the inner ear (for example, rubella or measles), as well as premature birth and congenital infections.³

Hearing loss is a very common condition affecting approximately one in seven of the population, with a steeply increasing incidence with age. There are approximately 613,000 people older than 16 years with severe to profound deafness in England and Wales. In the UK around 3% of people older than 50 and 8% of those older than 70 years have severe to profound hearing loss. There are more females than males with hearing loss although this is associated with females living longer rather than gender differences in causes of deafness.

The ageing population means that demand for both hearing assessment and associated interventions is set to rise over the coming years. The vast majority of the ageing population with poor hearing can benefit from a

³ [2 Clinical need and practice | Cochlear implants for children and adults with severe to profound deafness | Guidance | NICE](#)

direct primary care referral to adult hearing services, often based in the community, and do not require referral to an Ear, Nose and Throat (ENT) out-patient appointment prior to audiological assessment. This facilitates timely diagnosis and access to support for adults with poor hearing.

Older People are also less likely to have access to a car with the over 70 year age group with only 50% of women holding driving licences compared to 73% of men. Women, particularly older women, are therefore likely to be more dependent on public transport and would benefit from community/locality based services and those easily accessible by bus or train.⁴

Older people are therefore likely to be impacted more by the move to a central single implantable device hub as they tend to be high users of the service, some patients who are reliant on public transport may benefit from the outreach service that will be available.

Disability

Disabled people are ten times more likely to report ill health and also approximately half are likely to experience mental ill health. The Cwm Taf Morgannwg population report the poorest mental health status of all Health Boards in Wales. The proportion of people identifying themselves as disabled⁵ in the area affected is very similar to the proportion in Wales as a whole, 22.2% compared to 22.7%. There is a great deal of variation in disability among the health boards in the area affected. Cardiff and Vale UHB has the lowest proportion of its population reporting disability at 18.6%, while Cwm Taf at 26.1% has the highest proportion of its population reporting disability. At a local authority level Cardiff (18.0%), Monmouthshire (20.1%), the Vale of Glamorgan (20.3%) and Newport (20.8%) stand out with the lowest population proportions reporting a disability.

People who have a disability are twice as likely as people without a disability to have no access to a car (Office for Disability Issues 2009). Disabled people are also less confident in using public transport because of physical access issues but also because of staff attitudes (Framework for Action on Independent Living 2012).

Patients are eligible for non-emergency patient transport if the medical condition of the patient is such that they require the skills of ambulance staff or appropriately skilled personnel on or for the journey; and/or if the

⁴

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/514912/road-use-statistics.pdf

⁵ Disabled is defined as individuals whose day-to-day activities are either limited a lot, or limited a little

medical condition of the patient is such that it would be detrimental to the patient's condition or recovery if they were to travel by any other means.

Some people undergoing hearing loss surgery may be classed as disabled. To classify as disabled under the Equality Act 2010, you must have a physical or mental impairment that has a 'substantial' and 'long-term' negative effect on your ability to do normal daily activities.

The service will be able to provide and meet the needs of patients with any level of disability and be able to make reasonable adjustment to meet the person needs if required. However, based on the currently available evidence, no impact is anticipated on this protected characteristic group but may need further detail following the engagement process.

Sensory Loss

20% of people have impaired hearing and up to 70% of people aged over 70 have sensory loss. This can impact significantly on their ability to understand what they are being told and to interact effectively in a healthcare situation. In 2017 Cwm Taf UHB won an Action on Hearing Loss award for supplying hearing equipment to all secondary care wards and departments which help people to communicate effectively with health professionals thus ensuring dignity and confidentiality. This has been accompanied by staff training on use of the equipment and how to communicate with people who have difficulty hearing.

British Sign Language (BSL) is the preferred language of over 87,000 Deaf people in the UK for whom English may be a second or third language (A total of 151,000 individuals in the UK who can use BSL - this figure does not include professional BSL users, Interpreters, Translators, etc. unless they use BSL at home).

Sign languages are fully functional and expressive languages; at the same time they differ profoundly from spoken languages. BSL is a visual-gestural language with a distinctive grammar using handshapes, facial expressions, gestures and body language to convey meaning.

Contrary to popular belief, Sign Language is not international. Sign languages evolve wherever there are Deaf people, and they show all the variation you would expect from different spoken languages.

There are not derived from the spoken language of a country. Thus, although in Great Britain, Ireland and the United States the main spoken language is English, all three have entirely separate sign languages. As with spoken languages, a sign language can evolve from a parent sign language and therefore show affinities. For instance, due to historical and political links, Australian Sign Language and modern BSL share a common ancestor, and there are similarities between the two. American Sign Language (ASL)

bears a resemblance to French Sign Language (LSF) because Laurent Clerc introduced the “methodical sign system” developed by the Abbe de I’Epee in eighteenth century France into American Deaf education. There are also the regional dialects and “accents” which are present in every language.

Deaf people can choose from a number of communication methods. An individual’s choice will have been determined by many factors to do with their experience and the nature and degree of their deafness. The range includes:

- Sign Language
- Lip-reading
- Fingerspelling
- Deafblind fingerspelling
- Written communication

There are also signing systems that attempts to encode English into sign or to illustrate spoken English.

It can be difficult for a hearing person meeting a Deaf person for the first time, not knowing what communication methods they prefer, but the barriers are usually broken down once communication via the right method is established.

People with sight loss can also be affected by a changed location particularly if they are reliant on guide dogs. Others with low vision will benefit from clear signage, maps etc. It will be essential to take account the needs of people with sensory loss. This is also relevant to people with dementia.

There are already processes in place to support persons with disabilities, for example

- Easy read patient information leaflets
- Wheelchair access at places of safety facilities
- Translation services for those with Sensory issues

The proposed relocation to a central single implantable device hub is not considered to have any significant likely impact on patients based on their disability.

Ethnicity/Race

Cwm Taf Morgannwg have lower representation from ethnic groups other than white than Wales as a whole. However there are significant number of Polish, Portuguese and Czech people living in the Cwm Taf Morgannwg community and their access issues will need to be considered.

Overall the area affected is slightly more ethnically diverse than Wales as a whole, with 5.5% black and minority ethnic (BME)⁶ population compared to 4.4% BME population nationally. The area affected contains two of the four Welsh asylum seekers dispersal areas (Cardiff and Newport), and this is reflected in the higher BME populations in these areas compared to the other local authorities. Cardiff has the highest BME population at 15.3% with Newport having the second highest BME population at 10.1%. BME populations outside these local authorities in the area affected are in the range of 1.5% to 2%.

Some minority ethnic groups may have higher rates of hearing loss due to increased genetic risk associated with consanguinity and increased risk of childhood infections. Approximately 40% of children who are deaf and 45% of people younger than 60 years who are deaf have additional difficulties, such as other physical or sensory disabilities⁷.

Overall, language can represent a barrier across a number of areas, for example in accessing public transport and also in terms of finding and accessing health or social services.

Cultural differences may also be a factor in how people engage with health services. It can also limit understanding during diagnosis, treatment and during recovery. The use of translation services may be appropriate.

The language needs of patients from non-white ethnic groups will be taken into account when communicating information about the relocation of services.

Certain ethnic groups are less likely to access many of our services e.g. gypsies and travellers, and it will be important to take account of strategies which address this e.g. 'Travelling to A Better Future', Welsh Government. This has been a particular consideration in the development of the Health Board's Homeless and Vulnerable Groups Health Action Plan.

The proposed relocation to a central single implantable device hub is not considered to have any significant likely impact on patients based on their ethnicity. Approved translation services will be contacted at the earliest instance if it is suspected that one will be required.

Marriage and Civil Partnership

The number of people who are married or in a same-sex civil partnership living in Cwm Taf Morgannwg is the same as for Wales as a whole.

⁶ Black and minority population is classed here as any ethnicity not included under the white categories

⁷ [Overview](#) | [Cochlear implants for children and adults with severe to profound deafness](#) | [Guidance](#) | [NICE](#)

The proposed relocation to a central single implantable device hub is not considered to have any significant likely impact on patients based on their marriage status.

Pregnancy and Maternity

The proposed relocation to a central single implantable device hub is not considered to have any significant likely impact on patients based on pregnancy and maternity.

Religion

Research indicates that patients and families rely on spirituality and religion to help them deal with serious physical illnesses, expressing a desire to have specific spiritual and religious needs and concerns acknowledged or addressed by medical staff.

It is important that services take cultural needs into account. Some BME groups have a strong reliance on spiritual belief and practice; this has important implications for the way that they want to be cared for.

The proposed relocation to a central single implantable device hub is not considered to have any significant likely impact on patients based on their religion.

Sexuality Orientation

The proposed relocation to a central single implantable device hub is not considered to have any significant likely impact on sexuality. Patients of all sexualities would be given appropriate support when required.

Gender Reassignment

Information is not available on this group within the local community. However, recent research looking at the mental health and emotional wellbeing of transgender people has found rates of current and previously diagnosed mental ill health are high among this group. It is also recognised that this group find it particularly difficult to access services and their dignity and respect must be protected in both hospital and community settings.

Welsh Language

Public services have a responsibility to comply with the Welsh Language (Wales) Measure. This has created standards which establish the right for Welsh language speakers to receive services in Welsh.

In the Cwm Taf area, 11% of the population are able to speak Welsh according to the UK Census 2011. This compares with the Welsh average of 19%. 11% of Males and 14% of Females are able to speak Welsh compared with the Welsh average of 18% of Males and 20% of Females.

Service users who may prefer or need to communicate in the medium of Welsh may be required to access services at sites which do not have sufficient Welsh speaking staff. This could affect the service user's ability to communicate with service providers in their preferred language. Meeting the information and communication needs of Welsh speakers will need to be taken into account. Reading materials will also be made available upon request.

It will be essential to comply with the Welsh Language Act 1993 and all supporting strategies particularly the Bilingual Skills Strategy and the 'active offer' when planning for service change. In addition to this, the Welsh Language Commissioner has applied a new set of Standards throughout the Health Service in Wales which were issued in November 2018 and many must be met by May 2019. They cover staff and patients and we have a legal duty to meet them.

There are no identified impacts on the Welsh Language Measure of the potential change. If staff are not Welsh speakers approved translation services will be contacted at the earliest instance if it is suspected that one will be required.

Socioeconomic status

While socioeconomic status is not a protected characteristic under the Equality Act 2010, it is particularly relevant in relation to the protected characteristics. There is a strong correlation between the protected characteristics and low socioeconomic status

Approximately a quarter of households (25.2%) in the area affected has no access to a car, which is slightly higher than the proportion across the whole of Wales (22.9%).

Comparing the health boards in the area affected, Powys has the lowest proportion of households with no car or van at 15.0%, while Cwm Taf at 27.6% has the highest proportion with no car or van.

In terms of local authorities, Merthyr Tydfil (29.7%), Blaenau Gwent (29.0%), and Cardiff (29.0%) have the highest proportion of households with no car or van. Powys (15.0%) and Monmouthshire (15.2%) have the lowest proportion of households with no car or van.

Human Rights

At its most basic, care and support offers protection of people's right to life under Article 2 of the European Convention and the aim of this service is to preserve life through advanced treatment delivery. Reference has also been made to dignity and respect which is relevant to freedom from inhuman and degrading treatment (under Article 3 of the Convention) and the right to respect for private and family life (under Article 8).

Right to Life (taking reasonable steps to protect life) it is anticipated that having a single implantable hub with outreach model with a central Multi-disciplinary team provision will provide a safe and sustainable specialist auditory implant device service that meets national standards, will improve clinical outcomes and will have a positive impact on individuals right to have their life protected.

Summary Conclusion

What will the changes mean for the service?

- Quality standards are met
- Services are no longer spread too thinly across South Wales
- A more safe and sustainable service
- Single implantable Hub with outreach model with a central Multi Disciplinary Team provision
- Equity of access
- Improved outcomes for patients
- Support the majority of patients

Next Steps

Welsh Health Specialised Services will enter a period of targeted engagement, noting that a period of consultation may be required following this stage.

A commitment was made throughout the clinical option appraisal that Welsh Health Specialised Services would develop a Clinical Reference Group that would continue to evolve thinking throughout the engagement process. The first meeting will take place early October.

Discussions will remain ongoing with colleagues in Cwm Taf Morgannwg University Health Board regarding the staff affected by the temporary arrangements and who have moved with the service during 2019. Staff have been notified in advance that a targeted engagement process is due to commence.

Through the targeted engagement information will be gathered that will enable further development of the EIA.

DRAFT



Report Title	Designation of Provider Framework	Agenda Item	3.6		
Meeting Title	Joint Committee	Meeting Date	06/09/2022		
FOI Status	Open				
Author (Job title)	Senior Project Manager				
Executive Lead (Job title)	Director of Planning				
Purpose of the Report	To seek approval to adopt the Designation of Provider Framework as the WHSS team methodology for evaluating the appropriateness of Health Care Providers to become a designated provider of Highly Specialised and Specialised Services.				
Specific Action Required	RATIFY <input type="checkbox"/>	APPROVE <input type="checkbox"/>	SUPPORT <input checked="" type="checkbox"/>	ASSURE <input type="checkbox"/>	INFORM <input checked="" type="checkbox"/>
Recommendation(s): Members are asked to: <ul style="list-style-type: none">• Note the report; and• Approve the Designation of Provider Framework as the WHSS team methodology for evaluating the appropriateness of health care providers.					

DESIGNATION OF PROVIDER FRAMEWORK

1.0 SITUATION

To seek approval to adopt the Designation of Provider Framework as the WHSS team methodology for evaluating the appropriateness of Health Care Providers to become a designated provider of Highly Specialised and Specialised Services.

2.0 BACKGROUND

At the WHSSC Policy Group Meeting in March 2019, the Group discussed how designated providers of specialised services are agreed. It was noted that there were no clear written process in place and it was agreed that a process for assigning providers needed to be developed.

Through an iterative process, a draft framework for undertaking an evaluation has been developed.

The remit of this framework is intended to cover:

- Highly Specialised and Specialised Services currently commissioned by WHSSC,
- New or novel services or treatments not currently commissioned
- Existing non-contract services or treatments which may need to be routinely commissioned on an ongoing basis.

The Designation of a Provider of Specialised Services Framework has been developed to be considered as part of the WHSSC Commissioning Assurance Framework (CAF).

Under the scheme of delegation, the schedule of matters reserved to the Joint Committee includes the approval of the framework and strategy for performance management. WHSSC's Commissioning Assurance Framework (CAF) was approved by the Joint Committee on 7 September 2021, which included and is supported by the Performance Assurance Framework, Risk Management strategy, the WHSSC Escalation Process and Patient Experience and Engagement framework.

Once approved the Designated Provider Framework will support delivery of the CAF.

3.0 ASSESSMENT

As agreed by CDG Board, the draft framework presented at **Appendix 1** has subsequently been used as a working tool by both the Cardiac and the Cancer and Blood Commissioning Teams to undertake assessments of new provider requests to become a designated centre.

Practical application of the framework identified some areas where additional information and further clarification around a number of points would benefit from some minor amendments.

The document has subsequently been amended to reflect the proposed changes.

The framework outlines the roles and responsibilities for the specialised commissioning teams, and clearly defines the process and criteria for identifying new service providers.

The framework supports a two phased approach; an initial screening assessment followed by a full assessment if supported by the evidence following the initial assessment.

Four key assessment domains have been identified:

- Quality and Patient Safety
- Strategic Fit/equity of access
- Service deliverability/sustainability
- Value for money/affordability

The domains are supported by specific indicators and examples of documentation that would be considered important to inform the process.

The revised document is based on the practical application of the initial draft framework and is now considered to be fit for purpose for formal adoption of the methodology.

The framework does not apply to commissioning of secure or specialist Mental Health services, independently provided dialysis services, which have their own procurement and commissioning arrangements, or new or novel drugs which have their own assessment process.

The aim of the framework is to provide a basis for evaluating the appropriateness of health care providers' suitability and readiness to provide a specific specialised service to ensure that services commissioned by WHSSC are safe, effective and sustainable and provide compassionate and person-centred care.

The framework should not be used if it is identified that a full tender is required. In this instance advice must be sought from Procurement.

4.0 RECOMMENDATIONS

Members are asked to:

- **Note** the report; and

- **Approve** the Designation of Provider Framework as the WHSS team methodology for evaluating the appropriateness of health care providers.

Governance and Assurance	
Link to Strategic Objectives	
Strategic Objective(s)	Governance and Assurance Choose an item. Choose an item.
Link to Integrated Commissioning Plan	
Health and Care Standards	Governance, Leadership and Accountability Choose an item. Choose an item.
Principles of Prudent Healthcare	Choose an item. Choose an item. Choose an item.
NHS Delivery Framework Quadruple Aim	People in Wales have better quality and accessible health and social care services, enabled by digital and supported by engagement Choose an item. Choose an item. Choose an item.
Organisational Implications	
Quality, Safety & Patient Experience	WHSSC's strategic aim is, on behalf of the Health Boards, to ensure that there is equitable access to safe, effective and sustainable specialised services for the people of Wales, as close to patients' homes as possible, within available resources.
Finance/Resource Implications	No finance/resource implications
Population Health	No implications within the report
Legal Implications (including equality & diversity, socio economic duty etc.)	No legal implications within the report
Long Term Implications (incl. WBFG Act 2015)	-
Report History (Meeting/Date/Summary of Outcome)	CDG Board on the 04.07.22 – minor amendments to be made to decision making section
Appendices	Appendix 1 – Draft Designated Provider Framework



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Pwyllgor Gwasanaethau Iechyd
Arbenigol Cymru (PGIAC)
Welsh Health Specialised
Services Committee (WHSSC)

Commissioning Assurance Framework: Designation of Provider for Highly Specialised and Specialised Services

September 2022

Version 0.11

Document information	
Document purpose	Commissioning Assurance Framework
Document name	Commissioning Assurance Framework: Designation of Provider for Highly Specialised and Specialised Services
Author	Senior Project Manager
Publication date	TBC
Commissioning Team	All
Target audience	Directors of Planning; Directors of Commissioning; Directors of Nursing and Quality
Description	This document sets out the requirement for the designation of new service providers for highly specialised and specialised services.
Document No	
Review Date	Month/Year

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1. INTRODUCTION

This document describes the Welsh Health Specialised Services Committee (WHSSC) Commissioning Assurance Framework and sets out the requirement for the designation of new service providers for highly specialised and specialised services (referred to thereafter as Specialised Services). This framework applies to providers based in Wales or England.

The aim of this framework is to provide a basis for evaluating the appropriateness of potential new health care providers' governance structures, systems and procedures to ensure that future services commissioned by WHSSC are safe, effective and sustainable and provide compassionate and person-centred care.

It also outlines the roles and responsibilities for the specialised commissioning teams, and clearly define the process and criteria for identifying new service providers.

As the designated commissioners for Specialised Services, WHSSC procures services from providers that are most capable of delivering the best services for the people of Wales and the best value for money for the NHS in Wales.

2. CONTEXT

WHSSC strategic aim is, on behalf of the Health Boards, to ensure that there is equitable access to safe, effective and sustainable specialised services for the people of Wales, as close to patients' homes as possible, within available resources.

The remit of this framework is intended to cover:

- Highly Specialised and Specialised Services currently commissioned by WHSSC.
- New or novel services or treatments not currently commissioned
- Existing non-contract services or treatments which may need to be routinely commissioned on an ongoing basis.

This framework does not apply to commissioning of secure or specialist Mental Health services, independently provided dialysis services, which have their own procurement and commissioning arrangements, or new or novel drugs which have their own assessment process.

The Designation of a Provider of Specialised Services Framework has been developed to be considered as part of the WHSSC Commissioning Assurance Framework; [Corp-024](#).

3. DEFINITION OF PROVIDER

Providers under this framework are defined as

- NHS Wales Health Boards
- NHS Wales Trusts
- NHS England Foundation Trusts
- NHS England Trusts
- NHS Scotland Boards
- Non-profit and charitable providers of healthcare
- Independent sector providers of healthcare

4. ROUTES INTO THE FRAMEWORK

The intended routes into this framework are as follows:

- The formal WHSSC ICP process
 - To be initiated by the relevant planner
- The formal WHSSC LTA negotiation process
 - To be initiated by contract lead
- A proposal from a provider to become a designated provider
 - To be initiated by the relevant planner
- In situations where immediate action is required
 - In the event of a notified governance risk
 - With reference to the outsourcing framework
 - In the event that a service has reached Stage 4 of the WHSSC Escalation process and has been unable to demonstrate sufficient progress to achieve the WHSSC requested improvements and an alternative provider needs to be sourced

The framework should not be used if a full tender is required. In this instance advice and support must be sought from NHS Wales Shared Services.

5. ROLES AND RESPONSIBILITIES FOR COMMISSIONING TEAMS

The process to designate a service as a provider will be led by the relevant commissioning team. The team will be required to provide assurance that all necessary due diligence has been completed prior to making a recommendation for designation.

This will include but is not limited to:

- Liaison with Finance Team
- Liaison with procurement (if required)
- Liaison with the Quality Team
- Liaison with Welsh Health Legal (if required)
- Liaison with WHSSC Board Secretary
- Completion of the Designation Framework checklist (appendix 4)

6. DESIGNATION PROCESS

The framework is designed to help construct an evidence-base to consider whether a particular service, provided at a specific location, has the potential to be designated as a new or alternative provider and a mechanism for gathering the appropriate information to undertake a formal assessment of suitability to provide a service.

The following process should be applied when considering a designated provider.

1. Identify the desired long-term strategic direction for the service, given the needs of the local population and the current local configuration of health services;
2. The need to undertake engagement and consultation with key stakeholders and the scale of the engagement and consultation required at either stage of the process. See [Guidance for Engagement and Consultation on Changes to Health Services](#).
3. Notify providers and other affected groups that you are beginning work to identify a designated provider;
4. Work through the Framework as described below.

The Framework may be used:

A) In normal operations

When considering whether to designate a service as a provider, for example if there is insufficient capacity at a current provider to meet levels of demand, or there is an option to improve patient access to treatment and bring services closer to home.

When commissioning a brand new service.

When the existing non-contract services or treatments need to be routinely commissioned on an ongoing basis.

When a provider makes a request to WHSSC to be considered as a designated provider of a specialised service.

B) In distress or at the point of failure

WHSSC may need to de-commission services, for example in response to a provider request to stop providing the service or on the basis that there are sufficient alternative providers of those services and the provider is unable to meet new quality standards.

Additionally in the event that a service has reached Stage 4 of the WHSSC Escalation process and has been unable to demonstrate sufficient progress to

achieve the WHSSC requested improvements; WHSSC would seek alternative provision.

6.1 PROCESS TO AID DECISION MAKING

6.1.1 Initial assessment (screening)

Decisions about designating services will need to be evidence based. In the first stage the emphasis is on collecting some of the key evidence and highlighting data that will be required in subsequent stages of the framework.

The broad areas where information is required are:

- The features of the patients service being considered at a specific location;
- The features of alternative providers of similar services;
- Experience of the users of the services;
- The impact of a new or additional provider may have on the existing provider/s. For example the ability for the existing provider to continue to meet standards/activity levels should an additional provider be designated;
- Whether alternative providers of a similar service exist within a reasonable geographical area with similar patient outcomes;
- Whether alternative providers have sufficient capacity to manage increased activity as would be the case if a provider failed and could no longer provide services to patient demand.

- **The impact on health inequalities and /or inequity of access**

Framework users to consider in the event of having to cease providing a service or in considering designating a new/additional providers to whether this:

1. Has a significant adverse impact on the health of the persons in need of the service or significantly increases health inequalities;
2. Causes a significant increase in inequity of access to service provision.

- **The impact on interdependent services**

Any decision to designate or de-designate a service must take into account any supporting services due to the interlinked nature of health care services.

6.1.2 Decision Making

After consideration of the above points, the Commissioning Team should be in a position to make a recommendation to the Corporate Directors Group Board as to whether a service could potentially be designated as a provider.

The Commissioning Team will provide a report to the WHSSC Corporate Directors Group, setting out the recommendations from the initial assessment.

In the event that designation has not been supported following the initial assessment, WHSSC will inform the potential provider of the outcome of the assessment.

In the event that designation has been supported at this stage, WHSSC will inform the potential provider requesting the required supporting information and proceed to full assessment.

WHSSC will provide notification to any existing providers if there will be potential impact on that service.

6.1.3 Full Assessment

Four main domains have been identified to assess the specific conditions that providers will need to meet in order to become a designated provider of specialised services:

1. Quality and patient safety
2. Strategic fit/equity of access
3. Service deliverability/sustainability
4. Value for money/ affordability

Under each domain, the framework also outlines the:

- Quality indicators that can be used for both self-evaluation and for external assessment and quality assurance of service provision; and
- Themes related to each quality indicator that support evaluation against them.

Consideration should also be given to any procurement or legal issues.

• **Information Gathering**

To stand up to scrutiny, the process and decision making for the designation of a provider of Specialised Services needs to be based on evidence. The appropriate Commissioning Team will collect from the provider the relevant evidence from each of the domains, which can then be applied in each of the subsequent stages of the framework i.e. assessment and decision making.

The evidence available to assess will vary depending on whether the provider is an existing provider of a specialised service or seeking designation as a new provider. Examples of information evidence from each of the domains are outlined in appendix 1.

• **Assessment and Decision making**

The Commissioning Team will lead on the assessment of a provider's case to become a designated provider of a specialised or highly specialised service.

The Commissioning Team will be responsible for determining and gathering the required evidence from providers and any other appropriate information in relation to National Standards, Nice Guidance or quality outcomes that may be available to further inform the assessment.

In most cases a provider will be expected to complete a self-assessment against the WHSSC Service Specification/National Standards (see appendix 3 for an example) to support the assessment process.

The Commissioning Team will, where required and/or where appropriate seek further advice and support from clinical leads/Network leads in this assessment stage.

• **Decision making**

To assess the ability of a provider to deliver a service, the decision making evaluation tool (Appendix 2) which uses a system of criteria intended to encapsulate the key domains and indicators should be used to evaluate and support the Commissioning Team in forming their conclusions. However there may be other indicators which will be appropriate dependant on the service that is being evaluated. This information will be shared with potential providers in order to inform their proposal.

- **Decision Making Evaluation (in the event that more than one potential provider is being considered to provide a service)**

Scoring

1. Award a point score to the appropriate quality criterion: 1 (poor) to 4 (excellent).
2. Weight the individual scores for each domain. The weighted score is calculated by multiplying the score by the weight.
3. Add the total scores

Note the evaluation described above should not be used if a full tender is required. In this instance advice and support must be sought from NHS Wales Shared Services.

After completing the above stages, the Commissioning Team should be in a position to make a recommendation as to whether a service could potentially be designated as a provider.

The WHSS Team will present their assessment through the usual WHSSC governance processes as required:

- Corporate Directors Group Meeting (for approval)
- Management Group (for information or approval dependant on the situation)
- Joint Committee (for information)

7. APPENDICES

- 7.1 Domains and Indicators
- 7.2 Template - Evaluation and Scoring for Designating a Provider of a Highly Specialised or Specialised Service
- 7.3 Self-Assessment Tool example
- 7.4 Designation Framework Checklist

Appendix 1: Domains and Indicators

Domain	Indicator	Rational for Indicator	Potential Measures /sources of information **
Quality and patient Safety	<ul style="list-style-type: none"> • Safe delivery of care • Clinical Excellence 	<ul style="list-style-type: none"> • The provider complies with nationally agreed standards to ensure that people are safe and well cared for, and that their needs are met. • The provider takes into account national guidance and codes of practice in its service delivery. • People receive care and support that is based on relevant evidence, guidance and best practice • The provider has clear expectations for provision of high quality care and uses local and national audits and initiatives to monitor reliability. • Patient voice 	<ul style="list-style-type: none"> • National Standards • WHSSC Service Specification • Local quality arrangements/ standards • Relevant local clinical policies • HIW/CQC inspection reports • Clinical Audit data (including outcome, mortality, and morbidity data as appropriate) • PROMS/ PREMS • Information Governance documents/ procedures • NICE TA's
Strategic Fit/Equity of Access	<ul style="list-style-type: none"> • Long term direction and goal of the service • Opportunity to realign/ improve 	<ul style="list-style-type: none"> • The provider takes account of their ability to provide the regional/ supra regional service to enable equitable access for the people of Wales 	<ul style="list-style-type: none"> • Evidence of proposed patient pathway • Evidence of any discussions/ engagement with the referrer hospitals

	<p>current service provision for the population of Wales</p> <ul style="list-style-type: none"> Needs of the local, regional and or supra regional population of Wales 	<ul style="list-style-type: none"> Demonstrates alignment with the WHSS strategic plan for development of the service 	
Service Sustainability and deliverability	<ul style="list-style-type: none"> Safe and effective services for the population of Wales 	<ul style="list-style-type: none"> The provider can demonstrate sufficient and sustainable staffing capacity and capability to provide safe and effective care to patients The provider can demonstrate that it has considered the ongoing sustainability of the service. The provider can demonstrate that providing this service will not adversely affect specialist medical training. 	<ul style="list-style-type: none"> Staff to patient ratio's Evidence of appropriate demand and capacity planning (If not evidenced as part of the business case) Workforce plans Delivery of RTT

Value for Money/Affordability	<ul style="list-style-type: none"> Value for money Evidence based Service 	<ul style="list-style-type: none"> The provider can demonstrate that the service benchmarks well against other similar services The Commissioner has assurance that if the service is charged at local price (non PbR) that the price charged to Commissioner is the same as agreed by host commissioner 	<ul style="list-style-type: none"> Benchmarking against similar services/centres NHS England Tariff prices PLIC's Welsh Costing Returns Published outcome/audit data
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****** The examples are not an exhaustive list of what evidence may be required to support provider designation and will be dependent on whether the provider is an existing provider of a service or has the intention to provide.

Appendix 2: Example Template - Evaluation and Scoring for Designating a Provider of a Highly Specialised or Specialised Service

The submissions will be assessed against the following criteria and weighting*:

- Strategic Fit / Equity of Access (25%)
- Quality Standards/ Technical Specification (30%)
- Sustainability / Impact on other services / Pace of deliverability (weight 30%)
- Value for money / Affordability (15%)

* Weightings should be used as part of the assessment in the event of more than one provider proposal being received. The above weighting are for illustrative purposes only and will be determined by the Commissioning team as part of the assessment for the particular service.

The scales 1-4 have been agreed to score the evidence submitted against the four domains:

- 4 - Excellent. The proposal successfully addresses all relevant aspects of the criterion. Any shortcomings are minor.
- 3 - Good. The proposal addresses the criterion well, but a number of shortcomings are present.
- 2 - Fair. The proposal broadly addresses the criterion, but there are significant weaknesses.
- 1 - Poor. The criterion is inadequately addressed, or there are serious inherent weaknesses or cannot be assessed due to missing or incomplete information

The following indicators /statements within the criteria should be used to assist in the assessment but are not binding. Commissioning teams will agree the specific criteria for each domain at the start of assessment.

SCORE	QUALITY STANDARDS/ SERVICE/TECHNICAL SPECIFICATION	STRATEGIC FIT/ EQUITY OF ACCESS	SERVICE DELIVERABILITY AND SUSTAINABILITY	VALUE FOR MONEY/ AFFORDABILITY
4 - EXCELLENT	<p>Excellent proposal which clearly demonstrates the ability to meet all aspects of the service/technical Specification.</p> <p>Clear, well defined description of the quality agenda e.g. PROMS/ PREMS, patient engagement.</p> <p>Proposal demonstrates that the service benchmarks above other similar services.</p>	<p>Clear and precise description of how the centre will provide the regional /supra-regional service.</p> <p>Credible demonstration to deliver the service for Wales</p> <p>Clear links to prudent health care</p> <p>Clearly demonstrates how the delivery of this service sits with the organisations vision for XXXX Services</p> <p><i>*Strong evidence to support the deliverability of an additional service post covid</i></p>	<p>Sustainability and other consequences are clearly considered.</p> <p>Clear evidence of a strong Team in place to deliver the service</p> <p>Sets out the timespan for delivery, including recruitment</p> <p>Demonstrated consideration of the impact for future years and how the centres plans to manage future delivery beyond scope.</p> <p>Describes the impact this may have on the delivery of other XXXX services</p>	<p>Costs of the service are clearly outlined</p> <p>Costs are within the allocated WHSSC funding for the service</p> <p>Costs closely align to or less than the NHS England Tariff</p>

<p>3 - GOOD</p>	<p>Good proposal and most aspects of the service/ technical specification able to be met and clearly demonstrates the actions required to meet the service/technical specification in full</p> <p>Quality agenda considered with reference made to PROMS/ PREMS, patient engagement</p> <p>Proposal demonstrates that the service benchmarks well against other similar services</p>	<p>Sound proposal but some aspects of how the centre will deliver the regional /supra-regional service is missing.</p> <p>Some links to prudent health care</p> <p>Some evidence of how the delivery of this service sits with the organisations vision for XXXX Services</p> <p><i>*Good evidence to support the deliverability of an additional service post covid</i></p>	<p>Sustainability and other consequences are considered but not fully addressed</p> <p>Some evidence of a strong XXXX Team in place to deliver the service</p> <p>Sets out the timespan for delivery including recruitment timeline</p> <p>Some consideration of the impact for future years and how the centres plans to manage future delivery beyond scope.</p> <p>Describes the impact this may have on the delivery of other XXXX services</p>	<p>Costs of the service are outlined but some aspects are unclear</p> <p>Costs are closely within the allocated WHSSC funding for the service</p> <p>Costs align to NHS England Tariff</p>
<p>2 - FAIR</p>	<p>Some aspects of the proposal are unclear, unable to meet key aspects of the</p>	<p>Tenuous demonstration of how the centre will</p>	<p>Limited consideration of sustainability and other consequences.</p>	<p>Cost are in excess of WHSSC allocated budget but with</p>

	<p>service/technical specification</p> <p>Unable to clearly demonstrate the actions required to be taken to meet the service/technical specification</p> <p>Limited consideration of the quality agenda</p> <p>Proposal demonstrates that the service benchmarks in line or just short of other similar services but describes actions to improve</p>	<p>provide the supra-regional service.</p> <p>Tenuous links to prudent healthcare</p> <p>Limited evidence of how the delivery of this service sits with the organisations vision for XXXX Services</p> <p><i>*Limited evidence to support the deliverability of an additional service post covid</i></p>	<p>Limited evidence of a strong XXXX Team in place to deliver the service.</p> <p>No clear timescale set out for delivery.</p> <p>Limited consideration of the impact for future years and how the centre plans to manage future delivery beyond scope.</p> <p>Limited description on the impact this may have on the delivery of other XXXX services</p>	<p>some evidence to support the value of excess cost</p> <p>Costs do not align to NHS England Tariff</p>
1 - POOR	<p>Unclear, ill-defined proposal unable to meet the service/technical specification on a wide range of aspects</p> <p>Service benchmarks below other services</p>	<p>No clear description of the centre will provide the regional/ supra – regional service</p> <p>Proposal is ill-defined</p> <p><i>*No evidence to support the deliverability of an additional service post covid</i></p>	<p>Sustainability of the service not considered in the proposal</p> <p>No consideration of the impact for future years and how the centre plans to manage future delivery beyond scope</p>	<p>The cost of providing the service are unaffordable</p> <p>Costs are in excess of NHS England Tariff that would be considered cost effective</p>

			No description of the impact this may have on the delivery of other XXXX services	
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Appendix 3: Example Self-Assessment tool

A	XXXX			
	Service Spec/Standards Statement	How does the current service compare with the statement?	What is not currently in place? (What are your gaps?)	What needs to be done to meet the standard? What is in place to mitigate the risks associated with not meeting this standard?
A1				
A2				
A3				
A4				
A5				

Appendix 4: Designation Framework Checklist

Domain	Check	Supporting evidence/details
Quality and Patients Safety		
Strategic Fit/Equity of access		
Service deliverability and sustainability		
Value for Money/Affordability		



Report Title	Individual Patient Funding Requests (IPFR) Governance Update			Agenda Item	3.7
Meeting Title	Joint Committee			Meeting Date	06/09/2022
FOI Status	Open				
Author (Job title)	Senior Project Manager				
Executive Lead (Job title)	Director of Nursing				
Purpose of the Report	To provide the Joint Committee (JC) with an update regarding discussions with Welsh Government (WG) concerning the All Wales Independent Patient Funding Requests (IPFR) Policy, the work undertaken to update the terms of reference (ToR) of the WHSSC IPFR Panel and to seek support to undertake an engagement process on updating the ToR and a specific and limited review of the All Wales IPFR policy.				
Specific Action Required	RATIFY <input type="checkbox"/>	APPROVE <input checked="" type="checkbox"/>	SUPPORT <input type="checkbox"/>	ASSURE <input type="checkbox"/>	INFORM <input checked="" type="checkbox"/>
Recommendations: Members are asked to: <ul style="list-style-type: none">• Note that Welsh Government (WG) have confirmed that as the All Wales Independent Patient Funding Requests (IPFR) Panel is a sub-committee of the WHSSC Joint Committee, it is within its authority to update and approve the terms of reference (ToR),• Note that Welsh Government have confirmed that WHSSC can embark on an engagement process with key stakeholders to update the WHSSC IPFR Panel Terms of Reference (ToR) and to engage on a specific and limited review of the All Wales IPFR Policy,• Approve the proposal for WHSSC to embark on an engagement process with key stakeholders, including the All Wales Therapeutics and Toxicology Centre, IPFR Quality Assurance Advisory Group (AWTTC QAG), the Medical Directors, Directors of Public Health and the Board Secretaries of each of the Health Boards (HBs) and Velindre University NHS Trust (VUNT), to update the WHSSC IPFR Panel Terms of Reference (ToR) and on the specific and limited review of the All Wales IPFR Policy; and• Note that the revised documents will be approved by the Joint Committee prior to referral to the Health Boards for final approval; as requested in the letter of 28th July the revised documents will be shared with Welsh Government.					

INDEPENDENT PATIENT FUNDING REQUESTS (IPFR) GOVERNANCE UPDATE

1.0 SITUATION

To provide the Joint Committee (JC) with an update regarding discussions with Welsh Government (WG) concerning the All Wales Independent Patient Funding Requests (IPFR) Policy, the work undertaken to update the terms of reference (ToR) of the WHSSC IPFR Panel and to seek support to undertake an engagement process on updating the ToR and a specific and limited review of the All Wales IPFR policy.

2.0 BACKGROUND

There are both longstanding issues and risks arising from the COVID-19 pandemic related to the ToR of the WHSSC IPFR Panel.

A request to review the IPFR ToR was made to the JC in November 2020, which was not approved, as clarification was required on the governance process for approval of the ToR. Additionally, the Clinical Director of the All Wales Therapeutics & Toxicology Centre (AWTTC) which chairs the IPFR Quality Assurance (QA) group took the view that it was in the remit of the NHS Wales IPFR Managers group to amend the ToR and that WHSSC could not update its own ToR.

Separate to the ToR issues, on 3 December 2021 a request for a judicial review (JR) in the case of Maria Rose Wallpott (MW) – v- (1) WHSSC & (2) Aneurin Bevan University Health Board (ABUHB) was allowed and the decision of the WHSSC IPFR panel to refuse funding for treatment was quashed by the court. The basis of this decision was the court's interpretation of the existing NHS Wales Policy Making Decisions on IPFR, and legal advice from a Queen's Counsel (QC) Barrister, which indicated that the policy would need to be updated if its original and intended meaning was to be reinstated.

WHSSC have been in discussion with WG since then to discuss and agree an approach to updating the ToR and the IPFR Policy.

A productive meeting was held with WG on 10 May 2022 to discuss the complexities of the All Wales IPFR Policy process, specifically:

1. The authority of the JC to update and approve the ToR of the WHSSC IPFR Panel,
2. The governance process for updating the All Wales IPFR policy; and
3. Consideration of a wider review of the both the policy and governance framework of IPFR panels in Wales.

A letter was issued to WG on 23 May 2022 confirming the discussions from the meeting. WHSSC subsequently held discussions, with HB Committee Secretaries, and the All Wales Medical Directors Group, including the Chief Medical Officer (CMO), Deputy CMO (DCMO) and Chief Pharmaceutical Officer (CPO) on 1 July, to discuss how to proceed in strengthening the IPFR governance framework and an update was given to the JC on 12 July 2022,

WHSSC received a letter of response on 28 July 2022 which is presented at **Appendix 1** for information.

3.0 ASSESSMENT

3.1 WHSSC IPFR Panel ToR

In anticipation of the letter received from WG confirming the JC's authority to update the WHSSC IPFR Panel ToR in June 2022, the WHSSC Corporate Directors Group Board (CDGB) supported recommendations for the establishment of an internal IPFR review group to consider and make recommendations to support a revised ToR for the WHSSC IPFR Panel and to support a specific and limited review of the IPFR Policy.

The IPFR review group have considered the risks associated with the existing ToR and have developed a list of principles for consideration which are themed as follows:

- the membership,
- urgent cases,
- quoracy,
- meeting frequency; and
- documentation, reporting and monitoring.

Appendix 2 outlines the themes and proposed changes to the ToR.

3.2 All Wales IPFR Policy

The All Wales IPFR Policy is an NHS Wales policy owned by each of the seven HBs who have statutory responsibilities in relation to IPFR decisions. The outcome of any review must therefore be agreed by each of the HBs.

WHSSC is constituted as a sub-committee of all seven HBs and its JC can delegate certain activities to WHSSC directors as described in section 3.3.1 of the WHSSC Standing Orders (SOs). On this basis, which was supported by the CMO, DCMO and CPO, as well as members of the All Wales Medical Directors Group (AWMDG) at a meeting on 1 July 2022, a specific and limited review of the policy could be undertaken with comprehensive stakeholder engagement and it could be led by the WHSSC team. It was also agreed that progress should be reported to the JC but with final approval being sought from HBs, in keeping with the previous approach taken by WHSSC when making complex or contentious decisions and in keeping with WHSSC's SOs.

Following the JR and in anticipation of the policy being updated to reflect the original meaning, WHSSC have requested advice from David Locke QC (WHSSC's barrister during the JR) to support identifying amendments for the All Wales IPFR policy and the WHSSC ToR. This advice will be included within the scope of the specific and limited review of the IPFR policy.

3.3 Timeline for the Engagement Process

The timeline for the engagement process for the WHSSC IPFR Panel ToR and the specific and limited review of the IPFR policy is outlined below:

Date	Forum
6 September 2022	Joint Committee requested to support the engagement process
TBC	IPFR Policy Implementation Group (PIG)
TBC	WHSSC IPFR Panel, (including the new interim Chair)
TBC	IPFR Quality Assurance Group
TBC	All Wales Therapeutics & Toxicology Centre (AWTTC)
TBC	All Wales Medical Directors Group
7 October 2022	Board Secretaries Group
November 2022	Welsh Government
17 January 2022	Joint Committee approval and recommendation to HBs for approval
January 2023	HB Board Meetings for approval
January 2023	Welsh Government for information prior to adoption
14 March 2023	Joint Committee – Implementation Plan for approval

4.0 RECOMMENDATIONS

- **Note** that Welsh Government have confirmed that as the WHSSC Wales Independent Patient Funding Requests (IPFR) Panel is a sub-committee of the WHSSC Joint Committee, it is within its authority to update and approve the terms of reference (ToR),
- **Note** that Welsh Government have confirmed that WHSSC can embark on an engagement process with key stakeholders to update the WHSSC IPFR Panel Terms of Reference (ToR) and to engage on a specific and limited review of the All Wales IPFR Policy,
- **Approve** the proposal for WHSSC to embark on an engagement process with key stakeholders, including the All Wales Therapeutics and Toxicology Centre, IPFR Quality Assurance Advisory Group (AWTTC QAG), the Medical Directors, Directors of Public Health and the Board Secretaries

of each of the Health Boards and Velindre University NHS Trust (VUNT), to update the WHSSC IPFR Panel Terms of Reference (ToR) and on the specific and limited review of the All Wales IPFR Policy; and

- **Note** that the revised documents will be approved by the Joint Committee prior to referral to the Health Boards for final approval; as requested in the letter of 28th July the revised documents will be shared with Welsh Government.

Governance and Assurance	
Link to Strategic Objectives	
Strategic Objective(s)	Governance and Assurance Choose an item. Choose an item.
Link to Integrated Commissioning Plan	
Health and Care Standards	Choose an item. Governance, Leadership and Accountability Choose an item.
Principles of Prudent Healthcare	Reduce inappropriate variation Choose an item. Choose an item.
NHS Delivery Framework Quadruple Aim	People in Wales have better quality and accessible health and social care services, enabled by digital and supported by engagement Choose an item. Choose an item. Choose an item.
Organisational Implications	
Quality, Safety & Patient Experience	An Individual Patient Funding Request (IPFR) is the process Health Boards (HBs) and the Welsh Health Specialised Services Committee (WHSSC) use to consider providing a patient with a treatment, which is not routinely available in NHS Wales. The IPFR Quality Assurance Group (QAG) monitor the quality of the decisions made by HBs and WHSSC concerning IPFR decisions.
Finance/Resource Implications	No financial resources have been identified.
Population Health	No adverse implications relating to population health have been identified
Legal Implications (including equality & diversity, socio economic duty etc)	The purpose of the WHSSC IPFR Panel is to act as a Sub Committee of WHSSC and hold delegated Joint Committee authority to consider and make decisions on requests to fund NHS healthcare for patients who fall outside the range of services and treatments that a Health Board has agreed to routinely provide. The Governance framework for the WHSSC IPFR panel is outlined within the "All NHS Wales Policy Making Decisions on Individual Patient Funding Requests (IPFR)", published

	in June 2017, which includes specific terms of reference (ToR) for the WHSSC IPFR panel.
Long Term Implications (incl WBFG Act 2015)	WHSSC is committed to considering the long-term impact of its decisions, to work better with people, communities and each other, and to prevent persistent problems such as poverty, health inequalities and climate change.
Report History (Meeting/Date/Summary of Outcome)	<p><u>Joint Committee meetings:</u></p> <p>18 January 2022 - IPFR update</p> <p>15 March 2022 - IPFR update</p> <p>10 May 2022 - IPFR update</p> <p>12 July 2022 - IPFR update</p>
Appendices	<p>Appendix 1 – Letter from Welsh Government to WHSSC 29 July 2022</p> <p>Appendix 2 – Summary of Themes for the Engagement Process on the WHSSC IPFR Panel ToR</p>



Dr Sian Lewis
Managing Director
Welsh Health Specialised Services Committee

By email to: Jacqueline.evans8@wales.nhs.uk

28 July 2022

Dear Sian,

Re: WHSSC Individual Patient Funding Request (IPFR) Panel – Terms of Reference

Further to your letters of 1 April and 23 May, our meeting on 10 May, and the subsequent discussion with health board (HB) and NHS Trust Medical Directors on 1 July, this letter sets out a proposal for addressing the issues you have raised in relation to the operation of the Welsh Health Specialised Services Committee's Individual Patient Funding Request (IPFR) Panel and the review of the [NHS Wales Policy Making Decisions on Individual Patient Funding Requests \(IPFR\)](#) ("The IPFR Policy").

We are broadly in agreement that the current IPFR policy on the whole works well. Since introducing the policy in 2017 there has been a significant reduction in the number of IPFR requests made to NHS organisations and an increasing proportion of requests are approved. These measures indicate the IPFR policy is working for patients and their clinicians, and this is supported by the findings of the quality assurance processes put in place to support the policy.

That said, we note a request for a judicial review in the case of Maria Rose Wallpott (MW) – v- (1) WHSSC & (2) Aneurin Bevan UHB (ABUHB) was allowed and the decision of the WHSSC IPFR panel to refuse funding for treatment was quashed by the court. Subsequently, legal advice has indicated the IPFR policy is now to be interpreted in such a way that is contrary to the original policy intention and the IPFR policy would need to be updated if its original and intended meaning was to be reinstated.

Review of the All NHS Wales IPFR policy

We have taken the opportunity to revisit the findings of the independent review of the IPFR process and the report published by Welsh Government in 2017 which states (emphasis added):

“6. The patient’s clinical circumstances should be considered in comparison with other patients with the same condition and at the same stage in the progression of that condition.

7. The words “significantly different to the general population of patients” mean that the patient’s condition does not have substantially the same characteristics as other members of that population. For a patient to be significantly different, their particular clinical presentation was unlikely to have been considered as being part of the population for which the policy was made.”

This accords with your interpretation of the policy and strengthens the arguments for revisions to the wording of the IPFR policy to put beyond doubt how the policy should be interpreted. To that end we are content to agree a *de minimis* review of the IPFR policy subject to the conditions set out below.

- The IPFR Policy is an NHS Wales’ policy owned by each of the HBs who have statutory responsibilities in relation to IPFR decisions. The outcome of any review must therefore be agreed by each of the HBs; retaining an all-Wales approach to IPFR decisions is of primary importance given reducing variability in decision making has been a key success of the policy; and
- WHSSC is constituted as a sub-committee of all seven HBs and its Joint Committee (JC) can delegate certain activities to WHSSC directors as described in section 3.3.1 of the WHSSC Standing Orders (SO’s). On this basis, it was agreed at the All Wales Medical Directors Group (AWMDG) meeting, at which you were in attendance, that a de-minimis review with comprehensive stakeholder engagement could be taken forward by the WHSSC team. It was also agreed that this should report into WHSSC’s JC but with final approval being sought from HBs in keeping with the previous approach taken by WHSSC when making complex or contentious decisions and in keeping with WHSSC’s SOs.

Terms of Reference (ToR) of the All Wales IPFR Panel

The All Wales IPFR Panel is a sub-committee of the WHSSC JC and therefore it is within its authority to update and approve the terms of reference (ToR).

As agreed at the AWMDG meeting a process of engagement for both the de-minimis review of the Policy wording and the changes to the ToR should be undertaken with key stakeholders including the All Wales Therapeutics a Toxicology Centre IPFR Quality Assurance Advisory Group (AWTTC QAG), the Medical Directors and the Board Secretaries of each of the HBs and Velindre University NHS Trust (VUNT).

Following the engagement process, an amended Policy and new TORs should be submitted to the JC for consideration, and then go to HBs for final approval. Finally, we would ask you share any changes, agreed with HBs, with us prior to their adoption. As we discussed we would fully support moves to appoint a remunerated chair for WHSSC’s IPFR panel and would be happy to discuss this with you in the future.

We trust the letter provides a clear outline of next steps, however if you have any queries, please do not hesitate to contact us directly.

Given the implications for HBs we are copying this letter to Chief Executives, Medical Directors, Directors of Public Health, Board Secretaries/ Directors of Corporate Governance and the AWTTTC QAG, all of whom will have an interest.

Yours sincerely



Andrew Evans
Prif Swyddog Fferyllol/ Chief Pharmaceutical
Officer



Natalie Proctor
Pennaeth y Gangen Fferylliaeth a Rhagnodi/
Head of Pharmacy & Prescribing

Cc:

Chief Executives, Health Boards
Medical Directors, Health Boards
Directors of Public Health
Board Secretaries, Health Boards
All Wales Therapeutics and Toxicology Centre IPFR Quality Assurance Group

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GIG
CYMRU
NHS
WALES

Bwrdd Iechyd
Addysgu Powys
Powys Teaching
Health Board

CS/ CL

9th August 2022

Dr Sian Lewis
Managing Director
Welsh Health Specialised Services Committee

By email: sian.leewis100@wales.nhs.uk

Dear Sian

Individual Patient Funding Request Policy Review

I am writing further to the letter you received from Andrew Evans and Natalie Proctor dated the 28th July 2022. The letter set out a way forward for reviewing the NHS Wales Policy Making Decisions on Individual Patient Funding Requests (IPFR) ("The IPFR Policy").

The letter confirmed that legal advice had indicated the IPFR policy is now to be interpreted in such a way that is contrary to the original policy intention and the IPFR policy would need to be updated if its original and intended meaning was to be reinstated. The Welsh Government officials confirmed that they were content to agree a de minimis review of the IPFR policy subject to certain conditions. Health Boards have statutory responsibilities in relation to IPFR decisions and the IPFR Policy is a policy of health boards.

It is important that all health boards are content with the proposed review arrangements i.e., the delegation of the review to WHSSC officials by health boards through the WHSSC Joint Committee arrangements. Health Boards will wish to be assured that WHSSC officials will work closely with those responsible for Health Board IPFR panels and policy during the review and that any proposed amendments are approved through the Boards of health boards, as there will also be implications for secondary care.

As always, happy to discuss.

Yours sincerely

Carol Shillabeer
Chief Executive

c.c. CEOs Health Boards

Pencadlys
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Appendix 2

Themes and Suggestions for the Review of the WHSSC IPFR Panel ToR

The table below outlines a summary of the key areas that will be included in the engagement process.

Table 1 – Themes and Suggestions for the Review of the WHSSC IPFR Panel ToR

ToR Issue	Current	Proposed
Membership	<ul style="list-style-type: none"> • Independent Chair (who will be from existing members of the NHS organisations Boards) • Two Lay representatives • Nomination at Director level from each of the LHBs <p>A named representative from each of the seven Health Boards who should be a Director or Deputy/Assistant Director or named deputies of appropriate seniority and experience who can operate in the capacity of the primary representative. The intention will be to secure an appropriate balance of professional disciplines to secure an informed multi-disciplinary decision.</p> <p>A further two panel members may be appointed at the discretion of the Chair of the panel, for example a member of the Ethics Committee or a Senior Pharmacist. These members should come from outside the 7 Health Boards and one of which</p>	<ul style="list-style-type: none"> • Independent chair from open recruitment or existing members of the NHS organisations Boards • 2 Lay representatives** • HB IPFR Panel Chairs from each of the 7 Health Boards or nominated clinical deputy • 2 vice chairs (1 appointed from within the HB panel membership and 1 discretionary panel member (see below)) • WHSSC Medical Director or nominated deputy • WHSSC Director of Nursing or nominated deputy <p>In attendance from WHSSC:</p> <ul style="list-style-type: none"> • IPFR Manager/co-ordinator • Corporate Governance Manager • Other WHSSC staff as and when required <p>A further two panel members from the NHS in Wales may be appointed at the discretion of the Chair of the Panel, for example a member of an ethics committee.</p>

ToR Issue	Current	Proposed
	<p>would be nominated as the Vice Chair. The Chair of the panel will review the membership as necessary.</p> <p>In attendance from WHSSC</p> <ul style="list-style-type: none"> • Medical Director or Deputy • Director of Nursing or Deputy • IPFR Co-ordinator • Finance Advisor (if required) • Other WHSSC staff as and when required. 	
Urgent cases	<p>It is recognised that provision must be made for occasions where decisions may need to be made urgently. In these circumstances, the Chair of the IPFR Panel is authorised to make a decision outside of a full meeting of the Panel, within their delegated financial limits.</p>	<p>Provision will be made for occasions when a decision may be required urgently.</p> <p>Where possible a video conference panel will be held to consider urgent cases. If this is not possible due to the urgency of the request or availability of panel members, then the Managing Director of Specialised and Tertiary Service with either the Medical Director or the Director of Nursing Quality and the Chair (or Vice Chair) of the WHSSC Panel are authorised to make a decision outside of a full meeting of the Panel, within their delegated financial limits, on behalf of the Panel.</p> <p>Urgent cases will be reported at the next IPFR panel.</p>
Quoracy	<p>The Chair or Vice-Chair and representation from five of the seven Health Boards, three of which must be clinical representatives</p>	<p>The panel will be quorate if 4 of the 7 Health Boards representative, plus the Chair or vice chair and a lay person are present.</p>
Meeting frequency	<p>At least once a month with additional meetings held as required and</p>	<p>The IPFR panel will normally be held twice per month via video conferencing, face to face or a</p>

ToR Issue	Current	Proposed
	agreed with the Panel Chair. Video conferencing facilities will be available for all meetings.	combination of both. The Panel will run for no more than 4 hours with adequate breaks
Documentation, reporting and monitoring	The WHSSC IPFR Co-ordinator will clerk the meetings to ensure proper records of the panel discussions and decisions are made. An electronic database of decisions will also be maintained.	It is the responsibility of the WHSSC IPFR Co-ordinator to process all requests. The IPFR Co-ordinator will document the meetings to ensure panel discussions and decisions are appropriately documented. The meeting will be recorded for transcription purposes. The IPFR Coordinator will circulate draft minutes of the decision making to the Panel members within 5 days. Minutes will be ratified at the next IPFR panel meeting. The recording of the meeting will be deleted after ratification of the notes. An electronic database of all cases will be maintained.

**** Definition: Not currently registered as a healthcare professional, both lay (not currently a healthcare worker) and lay plus (no healthcare experience ever) (Health Research Authority (HRA) 2004) will be eligible.**

To further strengthen the ToR, the review group have proposed 3 additions:

- Declaration of Members' interest during the meeting,
- Situations where the panel cannot reach a consensus,
- Training for IPFR Panel members,
- Consideration of time commitment and remuneration of the Chair of the Panel (note the letter at **Appendix 1** is supportive of further discussions on remunerating the chair role).



Report Title	Annual Report 2021-2022	Agenda Item	3.8		
Meeting Title	Joint Committee	Meeting Date	06/09/2022		
FOI Status	Open				
Author (Job title)	Corporate Governance Manager				
Executive Lead (Job title)	Committee Secretary & Head of Corporate Services				
Purpose of the Report	The purpose of this report is present the WHSSC Annual Report 2021-2022 for approval.				
Specific Action Required	RATIFY <input type="checkbox"/>	APPROVE <input checked="" type="checkbox"/>	SUPPORT <input type="checkbox"/>	ASSURE <input checked="" type="checkbox"/>	INFORM <input checked="" type="checkbox"/>
Recommendation(s) Members are asked to: <ul style="list-style-type: none">• Approve the WHSSC Annual Report 2021-2022.					

ANNUAL REPORT 2021-2022

1.0 SITUATION

The purpose of this report is present the WHSSC Annual Report 2021-2022 for approval.

2.0 BACKGROUND

The Financial Reporting Manual (FREM) stipulates that statutory NHS bodies are required to publish, as a single document, a three-part annual report and accounts which includes a Performance Report, an Accountability Report and Financial Statements. As a hosted body under Cwm Taf Morgannwg UHB (CTMUHB), to meet this requirement WHSSC produces an Annual Governance Statement (AGS) and an Annual Report in accordance with section 9.0.2 of the WHSSC Standing Order's (SO's) which state:

9.0.2 The Joint Committee shall also facilitate effective scrutiny of its operations through the publication of regular reports on activity and performance, including publication of an Annual Report.

Under the scheme of delegation, the schedule of matters reserved to the Joint Committee includes the approval of the annual report.

3.0 ASSESSMENT

The Annual Report reflects on WHSSC's performance and its achievements over the last financial year and reflects on what was achieved in collaboration with partner organisations and stakeholders.

The draft Annual Report 2021-2022 was presented to the Integrated Governance Committee (IGC) on the 9 August 2022 and members were asked to provide any feedback prior to the document being finalised for submission to the Joint Committee meeting 6 September 2022 for approval. The Annual Report 2021-2022 is presented at **Appendix 1**.

The Joint Committee are requested to consider and approve the report, subject to any additional considerations the Committee may wish to include.

4.0 RECOMMENDATIONS

Members are asked to:

- **Approve** the WHSSC Annual Report 2021-2022.

Governance and Assurance	
Link to Strategic Objectives	
Strategic Objective(s)	Governance and Assurance Choose an item. Choose an item.
Link to Integrated Commissioning Plan	Approval process
Health and Care Standards	Governance, Leadership and Accountability Choose an item. Choose an item.
Principles of Prudent Healthcare	Public & professionals are equal partners through co-production Choose an item. Choose an item.
Institute for HealthCare Improvement Quadruple Aim	Improving Patient Experience (including quality and Satisfaction) Choose an item. Choose an item.
Organisational Implications	
Quality, Safety & Patient Experience	The report outlines how WHSSC have delivered effective quality, safety and patient experience.
Finance/Resource Implications	The Government Financial Reporting Manual (FReM) sets out core guidance for preparing government annual reports and accounts in the United Kingdom.
Population Health	Not applicable
Legal Implications (including equality & diversity, socio economic duty etc)	The Annual Report has been developed in accordance with section 9.0.2 of the WHSSC SO's which state: <i>9.0.2 The Joint Committee shall also facilitate effective scrutiny of its operations through the publication of regular reports on activity and performance, including publication of an Annual Report.</i> Approval of the report is delegated to the Joint Committee (Ref 40, page 51)).
Long Term Implications (incl WBFG Act 2015)	The report outlines that WHSSC is committed to contributing towards the achievement of the objectives of the Well-being of Future Generations (Wales) Act and aims to improve the social, economic, environmental and cultural well-being of Wales.
Report History (Meeting/Date/ Summary of Outcome)	1 August 2022 – CDGB – approved subject to minor amendments being made. 9 August 2022 – Integrated Governance Committee (IGC) – discussed and suggestions made for minor updates.
Appendices	Appendix 1 – WHSSC Annual Report 2021-2022.

