Report Title	Review of Specialised Commissioning in Haematology: Thrombotic Agenda Item  3.5 Thrombocytopenic Purpura			3.5	
Meeting Title	Joint Committee			<b>Meeting Date</b>	16/05/2023
FOI Status	Open				
Author (Job title)	Planning Manager				
Executive Lead (Job title)	Director of Planning				
Purpose of the Report	The purpose of this report is to outline the main findings and proposals of the review of specialised commissioning in haematology for Thrombotic Thrombocytopenic Purpura (TTP).				
Specific Action Required	RATIFY	APPROVE	SUPPORT	ASSURE	INFORM

# Recommendation(s):

Members are asked to:

- Note the current model of service delivery for TTP across Wales and the risks to
  equitable access to best treatment,
- **Approve** the transfer of commissioning responsibility for TTP from health boards to WHSSC ;and
- **Approve** the proposed preferred option to commission TTP for the population of south Wales from a designated comprehensive TTP centre in NHS England.

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## REVIEW OF SPECIALISED COMMISSIONING IN HAEMATOLOGY: THROMBOTIC THROMBOCYTOPENIC PURPURA

#### 1.0 SITUATION

The purpose of this report is to outline the main findings and proposals of the review of specialised commissioning in haematology for Thrombotic Thrombocytopenic Purpura (TTP).

WHSSC's Integrated Commissioning Plan 2022/23 included the commitment to review the remit of specialised commissioning in haematology. The review took place over quarters 2 and 3. This report is one of 3 separate reports on the findings and recommendations from the review.

The purpose of the current paper is to outline the main findings and proposals relating to the commissioning and provision of the service for Thrombotic Thrombocytopenic Purpura.

#### 2.0 BACKGROUND

WHSSC's work programme for 2022/23 included undertaking a review of the remit of specialised commissioning in haematology with focus on a number of specific clinical areas where WHSSC was aware of issues that had the potential to benefit from specialised commissioning. These were:

- The diagnosis and management of acute myeloid leukaemia,
- The management of AHSCT/BMT complications arising 100 days or more post transplantation,
- Salvage treatment for patients with high grade non Hodgkins lymphoma,
- Treatment for secondary immunodeficiency; and
- The pathway for the management of Thrombotic Thrombocytopenic Purpura (TTP).

Professor Chris Fegan, previously a consultant haematologist at Cardiff & Vale UHB, was commissioned by WHSSC to undertake the review. The review commenced in June 2022 via a workshop held with clinical stakeholders to engage in initial discussions on the challenges and opportunities across the clinical areas within the scope of the review. Clinical stakeholder meetings were then held with each health board. A final meeting with all stakeholders was held in November to discuss the findings and proposed recommendations.

#### 3.0 ASSESSMENT

The full report for TTP is contained in **Appendix 1**. This cover report provides a summary of the findings and options for TTP set out in the main report. It then then makes recommendations regarding future commissioning arrangements and further work towards ensuring a high quality, equitable and sustainable TTP service for Wales.

#### 3.1 Current commissioning arrangements

Under current commissioning arrangements for TTP in Wales, all diagnosis and treatment is currently health board commissioned. In contrast, in NHS England (NHSE), diagnosis and treatment for TTP is commissioned as a highly specialised service.

# 3.2 Epidemiology

TTP is a rare, life-threatening autoimmune blood disorder in which blood clots form in small blood vessels throughout the body. The clots can limit or block the flow of blood to your organs, such as your brain, kidneys or heart. Most cases of TTP occur spontaneously of unknown case, but a minority are congenital. It is very rare (incidence is estimated to be 4 to 6 cases per million population). In south Wales, there have been between 4 and 8 cases per annum. The primary acute treatment is plasma exchange (PEX) supported by immunosuppressive therapy and anti-thrombotic therapy.

## 3.3 Pathways

- North Wales patients suspected of having TTP are referred to the TTP centre in Liverpool (one of nine specifically commissioned TTP services in NHSE). Confirmation of diagnosis, acute treatment (PEX) and long term follow up is provided at the TTP centre,
- South Wales:
  - South west patients of Hywel Dda and Swansea Bay UHBs (plus Bridgend) suspected of having TTP are referred by their local haematology service to the renal service at Morriston Hospital for confirmation of diagnosis and acute treatment (PEX). Patients are referred to haematology for follow up,
  - South east patients of Cwm Taf Morgannwg, Aneurin Bevan and Cardiff & Vale UHBs suspected of having TTP are referred by their local haematology service to University Hospital of Wales for confirmation of diagnosis, oversight of acute treatment (PEX) and long term follow up; and
  - Powys residents in areas where secondary care and emergency pathways flow to NHSE are referred to the TTP centre in Birmingham.

#### 3.4 Key Findings

- The BCUHB clinical director for haematology has reported that the current pathway to the NHSE designated TTP service in Liverpool works well for patients,
- The TTP services at SBUHB and CVUHB are not specifically commissioned.
   Funding for patients from outside the provider health boards is provided through generic SLAs,
- TTP service at Cardiff & Vale:
  - There is no designated bed capacity for admitting TTP patients, no formal agreement with the haematology laboratory for out of hours TTP testing and no designated PEX service for TTP,
  - As a consequence, when a patient presents with TTP, there is risk of delay in organising the required acute service – bed, laboratory testing, PEX,
  - Consultant haematologist expertise in haemostasis and thrombosis is available to provide the clinical management and long term follow up for TTP patients (including for congenital TTP patients who are all referred to CVUHB),
- TTP service at Swansea Bay:
  - Patients are admitted to the renal ward (or to critical care if critically unwell) for PEX. There is usually rapid access to PEX,
  - The key test (ADAMTS 13) to confirm diagnosis can only be undertaken by the laboratory in Cardiff (so PEX may need to start before confirmation of TTP); and
  - While there is consultant haematologist follow up after PEX, there is currently no consultant sub-specialist in haemostasis and thrombosis in SBUHB.

#### 3.5 Options

The TTP service would seem to be appropriate for specialised commissioning: it is a rare condition (incidence is estimated to be 4 to 6 cases per million population) and in NHSE it is commissioned as a highly specialised service from a limited number of centres.

Patient's resident in north and mid Wales will continue to access TTP services in NHSE. Five potential options for the service model for south Wales are outlined in the attached report:

- Option 1: Maintain the current service configuration,
- The following risks were identified:
  - Potential inequity between north/mid and south Wales,
  - Risk in relation to timely access to PEX (particularly in south east Wales),
  - Risk in relation to ensuring equitable access to best care for post PEX management and long term follow up,
  - Option 2: Commission Cardiff as a single centre to provide a comprehensive service for all south Wales suspected and proven TTP patients
    - CVUHB has the necessary haematology and laboratory expertise,

- However, the constraints of bed availability and the ability to provide urgent PEX would need to be resolved,
- Option 3: Commission Swansea as a single centre to provide a comprehensive service for all south Wales suspected and proven TTP patients
  - The renal ward currently manages approx. 2 patients per year. Capacity would be required for a further 4 to 6 patients,
  - SBUHB would need to develop the capability to deliver the ADAMTS 13 test to confirm TTP, improve renal middle grade doctor cover and provide haematology consultant sub-specialty expertise in thrombosis,
  - There is potential that an alternative therapy to PEX may become available in the next 5 to 10 years which would have implications for the appropriate clinical specialty for delivering acute treatment,
- Option 4: Commission both Cardiff and Swansea as a single service (albeit on two sites) to provide a comprehensive service for all south Wales suspected and proven TTP patients
  - Potential to bring increased benefits to patients (e.g. common protocols, single MDT, shared expertise) and would be closer to home,
  - However, the service would remain delivered across 2 sites for a very small number of patients which may make it difficult to ensure a high quality and sustainable service which also provides value for money,
- Option 5: Commission one of the NHSE comprehensive TTP service centres to manage all patients from south Wales
  - The potential for all patients in Wales to benefit from the level of care provided at the centrally commissioned TTP centres in England,
  - Potential for equitable access to clinical trials run at the centres in England; and
  - This option would however have significant implications for travel and access, both emergency transfer for urgent treatment, and the impact on patients and families of accessing care a long way from their home.

# 3.6 Preferred Option

It is proposed that option 1, current arrangements, is rejected since there are recognised risks to quality and equity of service provision. Options 2 to 4 would require some additional investment to ensure sufficient capacity to rapidly admit and treat patients, as well provide appropriate long term follow up. However, these three options, which retain the service within Wales, have the challenge that the number of patients with TTP is small which may make it difficult to ensure a high quality and sustainable service which also provides value for money. Option 5 addresses this through commissioning the service from outside Wales. It is proposed that option 5 should be the preferred option. Within this option, there may be scope for elements of shared care provided locally with oversight from a designated TTP centre in England.

If TTP is agreed for transfer to WHSSC's commissioning remit, and option 5 (to commission from one of the NHSE comprehensive TTP centres) is agreed as the

preferred option, work would be undertaken to determine the provider Trust and service model for the south Wales population (based on the NHSE service specification). Given the short term challenges noted here and described in the attached report, it may be necessary that alongside this work actions are agreed with SBUHB and CVUHB to strengthen the existing service for TTP while the longer term model is agreed and implemented.

#### 4.0 RECOMMENDATIONS

Members are asked to:

- Note the current model of service delivery for TTP across Wales and the risks to equitable access to best treatment,
- **Approve** the transfer of commissioning responsibility for TTP from health boards to WHSSC; and
- **Approve** the proposed preferred option to commission TTP for the population of south Wales from a designated comprehensive TTP centre in NHS England.

Governance and Assurance			
Link to Strategic Objectives			
Strategic Objective(s)	Implementation of the Plan		
Link to Integrated Commissioning Plan	To review WHSSC's commissioning remit in specialised haematology.		
Health and Care Standards	Safe Care Effective Care Individual Care		
Principles of Prudent Healthcare	Reduce inappropriate variation Care for Those with the greatest health need first Only do what is needed		
NHS Delivery Framework Quadruple Aim	Choose an item. 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.		
<b>Organisational Implicat</b>	tions		
Quality, Safety & Patient Experience	The paper describes risks and challenges in the current service for patients requiring care for TTP.		
Finance/Resource Implications	The paper identifies the potential benefits of options for central commissioning through WHSSC. While these will have financial implications, these are not quantified in this report.		
Population Health	The purpose of the proposed options for commissioning through WHSSC is to ensure equitable access to optimal treatment for patients with TTP.		
Legal Implications	No legal implications have been identified.		
Long Term Implications	The paper consider the potential future benefits of central commissioning of the TTP service.		
Report History	6 February 2023 – CDGB 23 February 2023 - Management Group		
Appendices	Appendix 1 - Full report		

# Review of Specialised Commissioning in Haematology and Immunology

# Options Paper for possible central commissioning by WHSSC: Thrombotic Thrombocytopenic Purpura

# A) Background

Thrombotic Thrombocytopenic Purpura (TTP) is a rare (4-6 cases per million adults/year), potentially fatal autoimmune blood disorder. TTP is typically caused by the development of auto-antibodies to ADAMTS13 and much more rarely congenital deficiency (Cardiff presently manages 4 cases of congenital TTP). The normal role of ADAMTS13 is to cleave high molecular weight von Willebrand factor and prevent platelets adhering to endothelium so in its absence there is widespread thrombosis in arterioles and capillaries and more rarely larger blood vessels. TTP clinically manifests as "FRANT" – Fever, Renal impairment/failure, Anaemia (microangiopathic), Neurological disturbance (including seizures and stroke) and Thrombocytopenia.

It is an extremely serious condition as the untreated mortality is 90%, while prompt diagnosis and expert directed treatment can reduce this to less than 10%. However, although prompt treatment is essential to survival some patients may still be left with residual organ damage e.g. neurological, renal (ongoing dialysis).

Although the majority of cases of TTP are idiopathic, pregnancy, existing autoimmune disorders e.g SLE, HIV and hepatitis infections and drugs e.g quinine, ticlodipine, clopidogrel are all risk factors. Other conditions can mimic TTP especially during pregnancy most notably HELLP (<u>Haemolysis</u>, <u>E</u>levated <u>L</u>iver enzymes and <u>Low Platelets</u>), eclampsia, malignant hypertension, haemolytic uraemic syndrome, disseminated intravascular coagulopathy, metastatic malignancy and catastrophic antiphospholipid syndrome.

### B) Management of TTP

#### **Diagnosis**

The rarity of TTP and the widespread clinical presentation often means there is a delay in diagnosis which can prove catastrophic - approximately half of the deaths in the national UK registry occurred within 24 hours of presentation, primarily in women who make up two-thirds of all cases (Scully et al 2008). The cornerstone of diagnosis is clinical suspicion (FRANT symptoms and signs, plus more rarely ischaemic cardiac or abdominal pain), appropriate initial investigations: full blood count and blood film, reticulocyte count, coagulation screen including fibrinogen, urea and electrolytes (including creatinine) and lactate dehydrogenase, tests to rule out other possible diagnoses, followed by the confirmatory test of ADAMTS13.

Along with the tests undertaken to diagnose TTP or rule out other differential diagnoses, tests to assess the extent of organ damage are also typically undertaken including echocardiogram, CT brain (if neurological signs), and CT chest/abdomen/pelvis to check for underlying malignancy (if indicated)

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In south Wales, based on patients found to have low ADAMTS13 levels there have been 4-8 cases per year but an incidence of 4 - 6 per million/year (~9-13 cases per annum based on 2.3 million south Wales residents https://statswales.gov.wales/Catalogue/Population-and-Migration/Population/Estimates/Local-Health-Boards/populationestimates-by-lhb-age) would suggest some cases are being missed.

#### **Acute Treatment**

Given the speed TTP patients can deteriorate patients should be managed in an appropriately staffed expert unit capable of monitoring all the organs TTP may affect and intervening appropriately as and when necessary.

The treatment of TTP has evolved significantly over the last 15 years and now consists of:

- 1) Plasma exchange (PEX): Removes ADAMTS 13 antibodies and provide a source of ADAMTS 13 (Rock et al 1991).
- 1.5 plasma volume PEX (ideally using solvent detergent treated plasma) should start ASAP and always within 4 hours of diagnosis and continue for a minimum of 3 days the volume is then reduced to 1.0 plasma volume, if the patient is clinically responding. Typically, on average 7 days of PEX is required.
- 2) Immunosuppression: To reduce anti ADAMTS13 antibodies

Methylprednisolone (IV 1g/day) x 3 doses (daily) give immediately after PEX.

and

IV Rituximab 375mg/m2 administer after first plasma exchange (and at least 4 hours before next PEX therapy) and weekly thereafter up to a minimum of 4 doses although this may be given twice weekly in poorly responding patients (Scully et al 2011, Westwood et al 2013).

3) Anti-thrombotic therapy: Inhibit vWF-platelet interactions

Caplacizumab 10mg IV prior to PEX with 10mg subcutaneously daily after completion of each PEX, followed by a further 30 days of caplacizumab 10mg/SC daily (Peyvandi et al 2016, Scully et al 2019, Dutt et al 2022).

NICE approved caplacizumab in December 2020 as more rapidly results in platelet count normality, reduces number of PEX and volume of PEX required, reduced thrombotic events, reduced hospital stay including on critical care and improved survival. The list price of caplacizumab is £4,143 per 10-mg vial (excluding VAT; BNF online, May 2020) so an individual patient would in theory cost ~£120,000 for caplacizumab alone per acute episode, although NICE has negotiated a confidential commercial arrangement (discount) with the company enabling its availability to the NHS patients.

The acute treatment pathway may change significantly in the not too distant future (5-10 years) as at least 3 differing recombinant ADAMTS 13 and other anti von Willebrand factor products are presently being evaluated in clinical trials with the aim of negating the need for patients to receive PEX and possibly other therapies including caplacizumab.

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#### **Long-Term Follow-Up and Remission Management**

TTP was previously thought to only be an acute illness but long-term follow-up of TTP survivors reveals many potential chronic complications and morbidity in addition to the risk of relapse ~40% at 5 years (Doyle et al 2022). Patients with ongoing severe deficiency of ADAMTS13 are particularly likely to relapse but ongoing therapy with anti CD20 antibody therapy (rituximab or obinutuzumab) is very effective (96%) at preventing relapse. Therefore, lifelong serial ADAMTS13 levels should be monitored (3 monthly for first 12 months and then 6-12 monthly thereafter) in patients after remission along with urea and electrolytes, full blood count and LDH. Ciclosporin and splenectomy may be effective if anti CD20 antibody therapy fails to maintain high enough ADAMTS 13 levels.

Furthermore, ongoing specialist medical, physiotherapy and psychological supervision is required for survivors as long-term complications are very prevalent in both idiopathic TTP and congenital TTP patients including renal and cardiac impairment, hypertension, strokes and psychological problems including mood disorders, cognitive impairment, and reduced quality of life (Chaturvedi et al 2017, Falter et al 2017, Page et al 2017, Riva et al 2020). In fact, TTP survivors continue to have a higher all-cause mortality than reference populations mostly thought to be due to ongoing cardio and cerebrovascular risks (Sukumar et al 2022). Surviving patients should therefore have ongoing renal, cardiac and neurological assessments and social worker support.

The United Kingdom has been at the forefront of virtually all therapeutic clinical trials undertaken worldwide due to its expertise in managing such patients, the TTP registry and the provision of free acute medical care in this time sensitive disease. However, recent data showed that even within the UK (40 centres offering PEX) only 64.8% of patients commenced PEX within 24 hours due to diagnostic uncertainty/delays, the lack of on-site PEX, delays due to transport issues, bed availability, and the need for acute specialist input from multiple hospital teams which requires careful coordination to achieve the shortest diagnosis to PEX times. This study concluded that 27.8% of all TTP deaths were linked to delays in the initiation of PEX treatment (HaemSTAR Collaborators 2022). This very recent data had already been anticipated back in 2015 when it was proposed that due to the complexity of the diagnosis, the urgency and complexity of both the acute and long term management of TTP, the need for very cost-efficient use of extremely expensive resources and ultimately improve outcomes, a very few highly specialised comprehensive TTP care centres should be commissioned to manage this patient group (Dutt and Scully 2015). As a result, NHS England classified TTP as an ultra-rare orphan disease which requires highly specialised care and has commissioned only 9 centres (including Liverpool and Bristol) with an average catchment population of ~6 million which will manage on average ~ 2-3 new acute TTP patient/month. This will enable expertise across the TTP care pathway to be maintained as more frequent exposure to patients and more efficient use and better resource utilisation of very limited resources e.g. staff able to undertake PEX 24/7, psychological services etc.

There are both British (https://b-s-h.org.uk/guidelines/) and international guidelines (https://cdn.ymaws.com/www.isth.org/resource/resmgr/guidance\_and\_guidelines/ttp\_guideline/ist h\_ttp\_guideline\_september.pdf) as to how TTP should be managed.

#### C) The present management of TTP patients in Wales.

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At present no centre has been commissioned to provide a TTP service and payment is presently being provided through generic SLAs when a patient is referred from a UHB without a TTP treatment service to one that does.

At present, patients are managed through 3 UHBs, Betsi Cadwaladr, Cardiff and Swansea and meetings were held separately and together with all three on various dates:

9/8/22 - Earnest Heartin (BCUHB)

23/8/22 – Ann Benton (Swansea), Rachel Rayment (Cardiff), Edwin Massey (Welsh Blood Service/Velindre), Ian Langfield (joint Cardiff/Swansea) and Rachel Epps (WHSSC).

5/9/22 – Ann Benton and Clare Parker (both Swansea).

11/11/22 – James Griffin (NHSBT - -Bristol Apheresis/PEX) service.

18/11/22 – Thomas Holmes (Cardiff)

2/12/22 - Ann Benton and Clare Parker (both Swansea), Rachel Rayment, Thomas Holmes and Claire Main (all Cardiff) and Luke Archard (WHSSC).

#### 1) Betsi Cadwaladr UHB

Patients presenting with symptoms/signs/blood tests suggestive of a diagnosis of TTP usually come to the attention of the BCUHB haematology consultants (catchment population- 703,361) who review the blood film and blood results and if suggestive of TTP, urgently refer to the TTP comprehensive care centre in Liverpool where confirmatory diagnostic tests and all management (acute and chronic treatment and all long term monitoring and support) are subsequently delivered. The consultants at BCUHB are very satisfied with the care provided by Liverpool and would not wish the service for their patients to change.

#### 2) Cardiff and Vale UHB

The haemostasis and thrombosis consultants (total 5) at CVUHB have historically managed patients with suspected TTP from CVUHB, CTUHB (except Bridgend) and ABUHB – total catchment population ~1.4 million). However, CVUHB is not commissioned to provide a TTP service for patients outside CVUHB and as the condition is so rare, bespoke arrangement are required for each individual case. The TTP clinical care pathway at CVUHB involves suspected patients from CVUHB, CTUHB (not Bridgend) or ABUHB being admitted to critical care at the University Hospital of Wales (beds allowing) under the guidance of one of the haemostasis and thrombosis consultants. Despite no central funding, they also undertake the confirmatory ADAMTS 13 test within the Coagulation laboratory at UHW (result usually available within 1 hour of receipt of sample during routine hours). Although no formal agreement with the laboratory exists, the laboratory staff will come in out of hours on a good will basis, provided sample can be processed by 10-11pm. Despite no formal funding, they will also provide an ad hoc cover for weekends and bank holidays. Overview of the delivery of the acute TTP treatment pathway by the critical care staff is provided by the haemostasis and thrombosis clinical team. However, despite routine ("cold", in hours) PEX being provided by several teams within CVUHB (Haematology, Renal, Critical Care – all UHW based, and the Lipid clinic at Llandough hospital) due to their already routine very heavy service demands and limited number

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of expert PEX staff, it has at times proved very difficult to put a 24/7 team together to urgently deliver both in and out of hours PEX. Indeed, a recent patient had to be sent to Bristol as there was limited ability within CVUHB to provide all the necessary care an acute TTP patient requires.

Once a patient has been stabilised/improved and able to leave critical care, the patient is transferred to the haematology ward and PEX is continued by the haematology apheresis nurses. Following discharge, treatment and monitoring is delivered through the "autoimmune clinic" delivered in the haemophilia centre. Patients are managed through the existing Inherited Bleeding Disorders MDT with access to psychological, social worker and physiotherapy support. CVUHB presently manages 4 congenital TTP patients.

Due to bed and urgent PEX availability within UHW, there have been several discussions both within CVUHB and elsewhere (WHSSC) about how the TTP service limitations could be improved. Dr Thomas Holmes (Clinical Director of critical care within CVUHB) says that there is physical space for more patients to be managed within critical care at UHW if central funding could be secured. However, Dr Holmes confirmed that guaranteeing a 24/7 urgent PEX service may still not be possible as the necessary available expertise to provide urgent PEX may by chance still not be available and ideally further capacity for urgent PEX is required.

#### 3) Swansea Bay UHB

The acute element of the TTP service at SBUHB is led by the renal service who arrange the acute admission for the patient and lead on the inpatient management of the patients until they no longer require PEX. The diagnosis is made by the Haematologist in the local hospital and daily advice and discussions take place with the SBU Haematologists following transfer of the patients to Morriston Hospital. Dr Clare Parker is the current Renal Clinical Director at SBUHB. They provide a PEX service for all renal and non-renal indications and cover patients from SBUHB, HDUHB and Bridgend – catchment population ~930,000. As with CVUHB, SBUHB is not commissioned to provide a TTP service for patients and funding for patients from outside SBUHB is provided through generic SLAs. A patient suspected of having TTP is referred to the renal team and unless critically ill admitted to the renal ward at Morriston hospital for urgent treatment including 24/7 available PEX. Patients too unwell for the Renal ward are admitted directly to critical care where the renal nurses can initiate PEX if required. The potential diagnosis of TTP will have been made by a local or external haematologist based on the full blood count and blood film. The confirmatory ADAMTS 13 test is sent to the Coagulation laboratory at UHW in Cardiff but it can take up to 24 hours for a result to be provided. In the meantime, suspected TTP patients will have been transferred to a place of safety within SBUHB under renal team and commenced TTP therapy which can be stopped if the diagnosis is subsequently not confirmed. From December 2015 - August 2022, SBUHB have managed 14 proven TTP patients and since December 2019 admitted 7 patients with suspected TTP for TTP therapy, two of whom commenced PEX before the ADAMTS 13 result became available and an alternative diagnosis was identified. During the acute treatment phase the renal team led by Dr Parker manage the TTP patients including whilst on critical care but once they have stabilised/improved the haematology team at Singleton hospital take over further management e.g complete 30 days of Caplacizumab therapy, long term monitoring, prophylactic rituximab therapy if required etc. There is no issue with the 24/7 provision of PEX within SBUHB.

The availability of beds at SBUHB on the renal ward and/or critical care is usually not an issue but unfortunately in 2020 a patient had a prolonged stay in an ambulance whilst awaiting admission to

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Morriston hospital and a delay (12-18 hours) in finding a suitable bed once admitted, such that they suffered a catastrophic TTP event prior to commencing specific TTP therapy including PEX and died. A review of this case has led to changes in the admission pathway for suspected TTP patients and the team are confident this will not happen again although it must be recognised that the bed state will not be under the direct control of the Renal / Haematology team when the next TTP patient presents. There is a concern that the renal consultants undertake a 1 in 8 rota but with no middle grade cover out of hours and at present there is no specialist Haemostasis and Thrombosis consultant within SBUHB.

#### 4) Bristol Apheresis (including PEX) Service.

Bristol is one of the 9 comprehensive care centres for TTP established in England with Amanda Clark at Bristol Royal Infirmary providing the specialist Haematological input and the National Blood Service (NHS Blood & Transplant) in Bristol providing the plasma exchange service. The Bristol NBS apheresis service provides a 24/7 service undertaking over 300 apheresis procedures including 100 PEX per month. As the comprehensive care centre for TTP for the south west of England they not only provide PEX in Bristol they have a 24/7 urgent outreach PEX team ready to go to any centre as far as Truro and Barnstaple hospitals if for some reason the patients are not able to be transferred to Bristol Royal Infirmary. The main reason for non-admission to Bristol is bed availability. For those patients having to stay in their local hospital in south west England, Dr Clark and Dr Griffin along with the local haematologists provide the acute medical management for TTP patients. Once the acute episode has resolved all long term monitoring and therapy is provided by Dr Clark in Bristol giving all patients equal access to all the necessary expertise to ensure the maximum quality of care and survivorship as possible. On discussion with Dr James Griffin (Clinical Director Therapeutics at Bristol NHS Blood and Transplant), Bristol Apheresis service easily has the capacity to offer outreach 24/7 urgent PEX to the south Wales TTP patients (proven and suspected) – Bristol already provides some apheresis services to south Wales (extra corporal photopheresis for post stem cell transplant patients with graft versus host disease). The preferred Bristol model they could support, would be for patients to be admitted to one or two major centres with the expertise to diagnose, acutely monitor, provide the other necessary acute TTP treatments (e.g steroids, rituximab) and ultimately undertake the long term monitoring and treatment of surviving patients. There would of course be a charge for providing such a service from Bristol.

# D) Potential proposals for central commissioning of a TTP service by WHSSC.

The present TTP services in south Wales have evolved as a result of clinical need, not strategic planning, through generic SLAs whose purpose was never to develop services for such a rare and complicated disease. We do not know if the present services offer high quality care or not and whether changing the provision of this service would bring additional benefit to patients and cost efficiency.

#### 1) Leave the present service configuration as present.

TTP is a rare, acutely presenting and potentially lethal condition in the absence of immediate expert input, requiring the provision of extremely expensive therapies and as such fits completely within

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WHSSCs remit and purpose. At present there is inequality of care between north and south Wales with the former having the benefits of being admitted and managed by one of England's 9 TTP comprehensive care centres. Doing nothing leaves the 1.3 million patients in south east Wales with a very precarious service due to lack of beds and urgent PEX availability at UHW. Furthermore, Welsh patients are not being given the potential benefits of accessing new treatments through clinical trials. Cardiff has recently contributed to 3 TTP research projects (Alwan et al 2019, Dutt et al 2021, HaemSTAR Collaborators 2022) and although it opened a TTP therapeutic clinical trial, unfortunately due to the rarity of TTP no patients were enrolled and the study was closed.

# 2) Commission Cardiff as a single centre to provide a comprehensive service for all south Wales suspected and proven TTP patients.

At present Cardiff has the necessary Haemostasis and Thrombosis experts, medical cover (haemostasis and thrombosis consultant and dedicated haemostasis and thrombosis middle grade staff available 24/7) diagnostic capacity (ability to get quick ADAMTS 13 results from the UHW Coagulation laboratory and psychological support (moderate additional resources may be required) but would not be able to undertake this single centre role principally because of bed availability and access to urgent PEX. The Critical Care Director (Dr Holmes) has said that with a central commissioning model CVUHB critical care would be able to guarantee a bed with the necessary medical/nursing support but there may still be issues with the provision of urgent PEX. This additional PEX capacity could be urgently provided (within 4 hours) as an outreach service from the Bristol apheresis service. In the medium/long term it may be sensible for WHSSC to undertake a review of all the apheresis services it is presently funding within CVUHB (and possibly south Wales) to see if closer working and resource pooling between the various CVUHB apheresis teams would allow (possibly with some modest additional funding) repatriation of the PEX service to Cardiff from Bristol.

# 3) Commission Swansea as a single centre to provide a comprehensive service for all south Wales suspected and proven TTP patients.

At present Swansea provides a 24/7 TTP service through the Renal Directorate with support from the local haematologists. There has in the past been issues with bed availability which has hopefully been resolved but is there the bed and diagnostic/therapeutic capacity to provide the service for the whole of south Wales when there are presently no middle grade renal staff available out of hours, an absence of a specialist haemostasis and thrombosis consultant within SBUHB and no capacity at present, to undertake urgent ADAMTS 13 analysis? If Swansea was the single TTP service for south Wales, it would be most appropriate for the ADAMTS 13 testing to be done in house in Swansea and provide the out of routine hours support for south Wales. Another potential issue would be if PEX does in due course get superseded as an acute frontline therapy for TTP patients, is the Renal Directorate still willing to be the contact/admission team and provide the other urgent medical input – diagnostic and therapeutic - required?

4) Commission both Cardiff and Swansea as a single service (albeit on two sites) to provide a comprehensive service for all south Wales suspected and proven TTP patients.

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Through closer working (and probably some additional resources being provided through central commissioning) between the present providers of the TTP services within CVUHB and SBUHB – common care pathways, protocols, single MDT etc – it may be possible to improve the service within south Wales whilst allowing patients to be treated nearer home. However, there are several drawbacks to such a proposal including duplication of services on two sites for only a total 4-8 patients/year, real risk of inadequately funding two sites rather than pooling resources to provide a better single site service and failing to materialise the benefits presently enjoyed by north Wales patients attending the Liverpool comprehensive TTP service.

# 5) Commission one of the England comprehensive TTP service centres to manage all patients from Wales.

At present each of the two centres in south Wales are seeing on average 2 (Swansea) and 3 (Cardiff) acute TTP patients per annum which contrasts with the new English TTP centres who on average are seeing 30 patients/year. The standard of care for TTP patients is a minimum of very rapid diagnosis, urgent access to the expertise and complicated treatment, long term follow-up which includes monitoring not only for potential relapse but for the complications from the acute episode requiring specialist haematology, renal, cardiac, neurological, physiotherapy, social work and psychological support. Is it really possible with so few patients presenting to Cardiff and Swansea to offer the same level of care provided by an English TTP comprehensive treatment centres as enjoyed by patients in north Wales? For Cardiff and Swansea to provide this level of service either alone or as a combined service may not be cost effective and it may be both better for patients and potentially more cost effective to commission the TTP for south Wales patients from one of the 9 English centres. This would also allow Welsh patients access to potentially even better therapies via clinical trials open in the English centres. The downside is that transfer of patients to an English centre may not be easy but typically in England these TTP patients are transferred by helicopter if there is the risk of an excessive delay in road transfer. For south Wales this would be using the helicopter 4-8 times/year. There is also the issue of patients' family and friends potentially having to travel much further to visit the patient. The present service in North Wales already means patients from Bangor have to travel 70 miles to Liverpool but from Withybush hospital to Bristol, Birmingham and Liverpool is 135, 209 and 165 miles respectively. Obviously distances to the possible centres in England for the population of Cardiff and its surrounding areas would be significantly different. Clearly in England they have decided that the benefits of the cntralised model in terms of concentration of all necessary expertise, cost effectiveness and improved patient outcomes, outweigh the downside of having to travel further.

If any of options 2-5 are chosen, there is a real need for WHSSC to performance manage the newly commissioned service to ensure efficient resource utilisation and quality of care.

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Final draft TTP options proposal v 1.0 CF 091222

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Report Title	Cochlear and Bone Condu Implant (BCHI) Engagem Steps	_	Agenda Item	3.6
Meeting Title	Joint Committee		<b>Meeting Date</b>	16 May 2023
FOI Status	Open			
Author (Job title)	Assistant Director of Planning			
Executive Lead (Job title)	Director of Planning & Performance			
Purpose of the Report	The purpose of this report is to outline the targeted engagement process undertaken regarding Cochlear and BCHI services for people in South East Wales, South West Wales and South Powys, to present the findings from that process; and to establish the necessary next steps.			
Specific Action Required	RATIFY APPROVE	SUPPORT	ASSURE	INFORM

#### **Recommendations:**

#### Members are asked to:

- Note the process that has been enabled both in respect of a) the temporary urgent service change for Cochlear services and b) the requirements against the guidance for changes to NHS services in Wales,
- Note and consider the feedback received from patients, staff and stakeholders with respect commissioning intent,
- Approve the preferred commissioning model of a single implantable device hub for both children and adults with an outreach support model,
- **Support** the next steps specifically the undertaking of a designated provider process; followed by a period of formal consultation,
- Note the process that has been enabled to seek patient and stakeholder views in line
  with the requirements against the guidance for changes to NHS services in Wales; and
- Agree to take the outcome and proposed next steps through Health Boards for consideration.

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# COCHLEAR AND BONE CONDUCTION HEARING IMPLANT (BCHI) ENGAGEMENT & NEXT STEPS

#### 1.0 SITUATION

The purpose of this report is to outline the targeted engagement process undertaken regarding Cochlear and BCHI services for people in South East Wales, South West Wales and South Powys, to present the findings from that process and to establish the necessary next steps.

#### 2.0 BACKGROUND

There are approximately **613,000** people over the age of 16 with severe / profound deafness in England and Wales.<sup>1</sup>

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 and 16.

There are two specialist centres for Cochlear Implant services in South Wales:

- 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

Urgent temporary service change arrangements for the Cochlear Implant service located in the Princess of Wales Hospital, Bridgend has been in place since September 2019. The patients previously seen at the Princess of Wales Hospital in Bridgend are currently seen in the University Hospital of Wales, Cardiff.

There are three centres delivering the Bone Conduction Hearing Implant (BCHI) Service. Services from University Hospital of Wales, Cardiff and the other at Neath Port Talbot Hospital are funded by the Welsh Health Specialised Services Committee (WHSC) on behalf of all Health Boards.

The service delivered from the Royal Gwent hospital is funded by Aneurin Bevan University Health Board.

Cochlear and Bone Conduction Hearing Implant (BCHI) Engagement & Next Steps Page 2 of 12

 $<sup>^{1}</sup>$  Overview | Cochlear Implant implants for children and adults with severe to profound deafness | Guidance | NICE

#### 3.0 ASSESSMENT

#### 3.1 Current Position

Following notification from Cwm Taf Morgannwg in 2019, that the Health Board would no longer be able to provide the Cochlear service from Princess of Wales in Bridgend, due to issues of workforce and sustainability, an urgent temporary service change was enabled that resulted in all patients from South West Wales, South East Wales and South Powys being seen at the University Hospital of Wales within Cardiff and Vale University Health Board.

The Covid19 pandemic delayed the ability to proceed with public engagement / consultation. The process restarted as appropriate within the context of other recovery and commissioning priorities.

When recommenced; a number of processes were enabled to determine a preferred commissioning model onward; and ensure a solid background to the engagement process. The components of this were:

- A clinical option appraisal
- An independent assessment of the options by an external assessor (from a comparable service in NHS England)
- A financial appraisal of the options

Horizon scanning and review of models of specialist auditory provision in other parts of the UK resulted in WHSSC considering the entire / potential services within its remit. This would allow the commissioning ambition for a Centre of Excellence in Wales which would include Cochlear implants, Bone Conduction Hearing Implants, and middle ear implants (should they be approved through a process which is enabled in 2023).

This information was brought together and considered by both the Management Group and the Joint Committee, who then supported both the content and process relating to a period of engagement on a 'a single implantable device hub for both children and adults with an outreach support model'.

Agreement was reached through Health Boards during September 2022, for a period of targeted engagement with regard future provision of both Cochlear and Bone Conduction Hearing Implants (BCHI).

#### 3.2 Aim of the targeted engagement

Early discussions were held with Community Health Councils (CHC's) and a targeted engagement was agreed as the affected patient cohort were small in numbers and it was a highly specialised service.

The scope of the engagement was to seek support or otherwise for a Centre of Excellence for Specialist Auditory Devices (including BCHI, Cochlear and middle ear implants – subject to approval of the latter).

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#### 3.3 Process

The process, which was agreed with the CHC, was of a targeted engagement with those accessing the service. Because BCHI services were also included within the scope of the engagement, a broader stakeholder cascade of information was made.

Table 1: Summary of the Reach

GROUP	METHOD	
Patients	952 patients cascaded via their local clinical teams	
Staff	All documentation made available to clinical teams via the Heads of Service	
Stakeholders	National organisations managed by WHSSC  Cascade of documentation via:  • ABUHB Stakeholder network & website • BCUHB Stakeholder network & website • CTMUHB Stakeholder network & website • CVUHB Stakeholder network & website • HDUHB Stakeholder network & website • PTHB Stakeholder network & website • SBUHB Stakeholder network & website	

A number of materials were produced to support the process:

- · Core consultation document (English and Welsh),
- Summary document (English and Welsh),
- · Easy read document (English and Welsh),
- Video (with BSL),
- · Questionnaire,
- Equality Impact Assessment (EQIA); and
- Publications on Health Board websites signposting to the engagement.

#### 3.4 Outcome

There were 201 responses to the questionnaire, of these, 5 were from organisations, and 196 were from individuals. There was also a detailed written response from the clinical community, submitted via the Audiology Standing Specialist Advisory Group (ASSAG). The data from the questionnaire is reported against the engagement questions at **Appendix 1**. The ASSG response is presented at **Appendix 3**.

A thematic analysis has been undertaken against the data. The key themes that emerged from the analysis are outlined below:

Table 2: Key Themes of Analysis

Theme	Summary
General support for the proposed change	There was good support for a single implantable device hub with 74% of respondents agreeing to the preferred option. The qualitative information presented in <b>Appendix 2</b> is worthy of further note.
No support for the proposed change	There were 8% who disagreed with the preferred option and 18% who had no particular view. The qualitative information presented in <b>Appendix 2</b> is worthy of further note.
<ul> <li>Access, travel, location, parking &amp; costs</li> </ul>	The four most consistent themes were of accessibility, i.e. location of services particularly the single hub centre, sustainability, the patient experience and travel and journey times for patients.
Staff and resources	There were a number of statements related to either staffing levels or service funding.
Service design	A number of suggestions/comments were made in respect of service design.
Service feedback/general comments	There was good support and positive comments from respondents about the current provision of services, how they had received excellent quality care and were well looked after by the staff. There were also some areas suggested for improvement.
Comments on process and options	A number of issues of process were raised, these predominantly related to the length of the process (which delayed through COVID); the separation of Cochlear from BCHI and the separation of children from adults, these responses were predominantly from the clinical community.
Waiting times	The majority of comments were with regard waiting times.

All responses are reported against the themes at *Appendix 2*.

(Note - some quotes have been used for illustration in the text, however should not be considered in isolation of the data presented in the appendices).

#### 3.5 Findings and Exploration

The majority of respondents (74%) were **supportive of the preferred option**. Reasons stated included the benefits of a single Centre of Excellence, all staff in the same place, continuity of personnel and an anticipated benefit with regard waiting times and staff availability. There were examples of respondents being supportive of the preferred option, however also aware of a broader impact for example on travel times/distance and associated costs. These have been captured in the thematic report.

I think that this will be a positive move, everything will be easily accessible and all at one place

The most important thing is the experience of the person setting up the hearing aid to give maximum benefit. If you have to travel for this it is worth it.

High volume surgical sites' are key for good outcomes. At the same time follow up services should be 'local to a patient' for better compliance & outcomes

Having one team of skilled experienced specialists in one hub can be a huge benefit to implant surgery. It is however vital that regional outreach support is maintained as access from across Wales to one central hub is not practical for all

A smaller number of respondents (8%) who offered their views as to why they **would not support the preferred option**, with the dominant reason being linked to travel impact for both patients and staff.

Too large, anonymous, patients are not familiar with staff and feel insecure and apprehensive. Harder for relatives to visit.

The view of the professional group was that there is support for the centralisation of Cochlear services, but not for BCHI, due to the reasons outlined in **Appendix** 3. (Permission to publish the clinical communities' response has been gained).

The highest number of consistent themes from the engagement process were in the areas of: **Access, travel, location, parking & costs.** Cochlear services have all been on a single site since 2019, as such whilst the inconvenience of travel to and parking at a single sight, is acknowledged it does not appear to have impacted attendance at clinics to date.

Accessibility is the key problem for me, already having issues with train strikes, limited timetables for all public transport.

People living in far reaches of the area that provides hearing devices have a hard time reaching one hub, especially in inclement weather

With regard **staff and resources**; the main areas of feedback here were with regard adequate staffing numbers; appropriate training; sufficient finances to support the service, and the right level of specialist staff.

The success of delivering the future aims is very much dependable upon consistent funding

For all of the above to be achieved I think will take a long time. It needs much more funding.

Through the responses, a number of observations and suggestions were made with regard **Service Design**. These included increased access through outreach clinics; weekly hub presence; increased use of technology and new advances in treatment; working to agreed standards, and provision of emotional support to families.

Local outreach and access, including audiology appointments and rehabilitation appointments would enable ease of access

Many respondents took the opportunity through the engagement process to offer general commentary on their experience of the service and some personal patient stories. These collectively offer a rich picture and should be considered in forward planning and delivery of service. (Note relevant section in **Appendix 2**).

A number of comments were also received on the **process** that had been followed. Specifically comments predominantly related to separating Cochlear

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and BCHI; separating adult and children; the length of time that the process has taken since the urgent temporary change in 2019; and a few respondents suggested they would prefer a different option. There was some suggestion that insufficient regard had been given to the clinical view, and that the incorrect guidance had been used to inform the work, and that there was inconsistency in two of the resources supporting the engagement information.

A theme also emerged with regard to **waiting times**, some regarding aspiration and hope for shortened waiting times as a result of a centralised service, and others with regard actual experience. Some respondents for example, suggested that the proposed single implantable device hub would offer a more timely service with equitable waiting times for all patients, conversely, some respondents commented that it could increase waiting times due to the increase in volume of patients trying to access the service.

The proposed mitigations arising from the engagement are as follows:

I am wondering if this will have a positive impact on waiting times.

Table 3: Proposed Mitigations

Theme	Mitigation
Access, travel, location, parking & costs	Whilst a single central location is proposed (site to be identified) the service model should a) have a central MDT b) centralised operations c) local follow up, monitoring and modifications. Commitment will remain to local outreach clinics.
Staff and resources	The financial option appraisal undertaken to inform this work demonstrated that there is sufficient funding within the service, and that finance was not a driver for this work. WHSSC will review further service developments as part of its normal commissioning processes.
Service design	Issues raised regard: access through outreach clinics; weekly hub presence; increased use of technology and new advances in treatment; working to agreed standards, and provision of emotional support to families will be included within service

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Theme	Mitigation
	modelling and implementation discussions.
	Further understanding is to be had with regard availability of soundproofed rooms
Service feedback/general comments	Feedback to be shared with clinical teams delivering services, and suggestions (as appropriate) used to inform future service modelling
<ul> <li>Comments on process and options</li> </ul>	Further engagement is required with the Clinical Reference Group regarding the specifics of the issues raised. Also further discussions with the Chair of ASSAG will take place.
	With regard the specific point raised by the clinical community on the relevance of the guidance - We acknowledge the reference to the latest policy. Both the 2013 and 2016 policies are listed as current published documents on the NHS England website and have therefore been used to inform the review of the services.
	We acknowledge that BCIG standards are for the Cochlear Implant service only. The BCHI standard" a centre should undertake a minimum of 15 BCHI per year" has been quoted from the Clinical Commissioning Policy: Bone Anchored Hearing Aids, April 2013. Reference NHSCB/D09/P/a.
Waiting times	Monitoring information on waiting times to continue to be regularly reviewed.

#### 3.6 Conclusion and Next Steps

The engagement process outlined above has tested support or otherwise for the commissioning of a single implantable hub for South East Wales, South West Wales and South Powys. The patient voice appears to give strong support, whilst there is further engagement to be held with the clinical community on the future service model. A number of mitigations have been highlighted in the response to the patient voice.

The clinical view has been consistent throughout the process, and WHSSC has again considered the issues raised by the clinical community. The feedback obtained through the consultation process does not appear to have identified any information (aside of the need to profile available sound proof rooms), which had not previously been taken into account when the preferred commission model was agreed. Specifically:

- The preferred option will enable the safe and sustainable delivery of services for patients requiring an implantable hearing device which will include:
- Assessment by a multi-disciplinary team that is able to offer access to all types of (commissioned) hearing implants
- Guidance on standards for Bone Conduction Hearing Implant (BCHI) services comes from a consensus statement of experts, which states:

That BCHI fitting should take place in a specialist auditory implant device centre performing at least 15 implants per year. Clinical Commissioning Policy

In addition, the implementation of the Duty of Quality (Health and Social Care (Quality and Engagement) (Wales) Act 2020) means that WHSSC now risks legal challenge if it derogates from established best practice.

Taking all of the above into account and, in particular, the strong patient support for the single centre, WHSSC continues with the ambition to commission a Centre of Excellence for all Auditory Specialist Implantable Devices (Cochlear, BCHI and middle ear if supported).

To date, no location has been specified for the centre, as such WHSSC will now move forward into a second phase of consultation which includes a preferred location. To do this, a designated provider process will need to be enabled, this means WHSSC will ask providers to submit a proposal outlining if they wish to deliver the centralised service, and if so how they can deliver the service. WHSSC will develop clear criteria against which the service proposals are assessed and will use this information as the basis of consultation on a preferred option.

In the meantime, all Cochlear patients will continue to be seen at Cardiff and Vale University Health Board. There will be no immediate change to the provision of BCHI.

In line with Welsh Government guidance for engagement and consultation on changes to health services in Wales, guidance is required from Community Health Council colleagues with regard the process that has been enabled, the outcome of the exercise and proposed next steps. Formal discussions to agree next necessary steps are to take place with Community Health Councils shortly. The final report to Joint Committee will include their recommendation.

#### 4.0 RECOMMENDATIONS:

Members are asked to:

- **Note** the process that has been enabled both in respect of a) the temporary urgent service change for Cochlear services and b) the requirements against the guidance for changes to NHS services in Wales,
- **Note** and **consider** the feedback received from patients, staff and stakeholders with respect commissioning intent,
- **Approve** the preferred commissioning model of a single implantable device hub for both children and adults with an outreach support model,
- **Support** the next steps specifically the undertaking of a designated provider process; followed by a period of formal consultation,
- Note the process that has been enabled to seek patient and stakeholder views in line with the requirements against the guidance for changes to NHS services in Wales; and
- **Agree** to take the outcome and proposed next steps through Health Boards for consideration.

Governance and Assurance			
Link to Strategic Objectives			
Strategic Objective(s)	Governance and Assurance		
Link to Integrated	Cochlear Implants and BCHI are deemed a Specialist		
Commissioning Plan	service, and as such commissioned by WHSSC		
Health and Care	Governance, Leadership and Accountability		
Standards	Safe Care		
	Individual Care		
Duin sinds of David and	Dadwa in a grant with a societie of		
Principles of Prudent	Reduce inappropriate variation		
Healthcare	Public & professionals are equal partners through co-		
	production		
NHS Delivery	People in Wales have improved health and well-being with		
Framework Quadruple	better prevention and self-management		
Aim	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		
Organisational Implications			
Quality, Safety &	This engagement has been undertaken in order to respond		
Patient Experience	to issues of service sustainability and patient experience.		
Finance/Resource	A financial option appraisal has been undertaken to inform		
Implications	this work		
Population Health	No adverse implications relating to population health have been identified.		
Legal Implications	An EQIA was undertaken to inform the work. A number of		
(including equality &	issues have arisen through the process with regard socio		
diversity, socio	economic issues, specifically as related to travel, location		
economic duty etc.)	and cost. These are detailed within the report, along with		
	any available mitigating actions.		
Long Term	The framework has been developed cognisant of the		
Implications (incl.	relevant long term implications		
WBFG Act 2015)			
Report History	MG 27 April 2023		
(Meeting/Date/	CDGB – 2 May 2023		
Summary of Outcome	,		
Appendices	Appendix 1 - Presentation of data against questions asked Appendix 2 - Thematic analysis		
Appendices	Appendix 3 - Professional Community response		
	Appendix 3 - Froiessional Continuinty response		



Pwyllgor Gwasanaethau lechyd Arbenigol Cymru (PGIAC)

Welsh Health Specialised Services Committee (WHSSC)





# **APPENDIX 1 QUESTIONNAIRE RESPONSES**

ENGAGEMENT ON FUTURE PROVISION OF COCHLEAR AND BONE CONDUCTION HEARING IMPLANTS FOR SOUTH EAST WALES, SOUTH WEST WALES, & SOUTH POWYS



Pictures - Copyright Cochlear Limited

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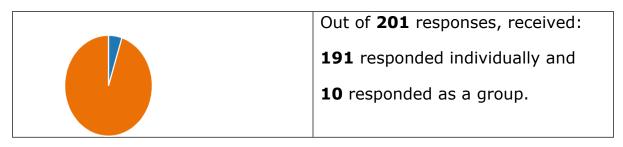


# PRESENTATION OF DATA AGAINST QUESTIONNAIRE

#### 1. Presentation of data

There were 201 responses received to the engagement process.

**Table: 1 Total Number of respondents.** 



There were 10 group responses however, were from the following organisations:

- 6 were from Audiology departments across South East, South West and South Powys
- 1 was from the National Deaf Children's Society
- 1 was from RCT People First
- 1 was from the Audiology Standing Specialist Advisory Group/Audiology Heads of Service Group
- 1 was from the Centre of sign, sight and sound

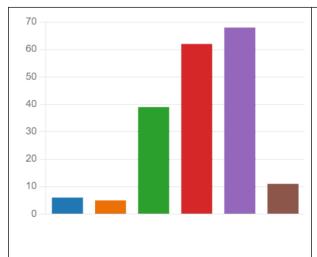
# **Demographics and Geographic Profile of Respondents**

The age, gender and national identity profile of respondents is shown below:

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#### **APPENDIX 1**

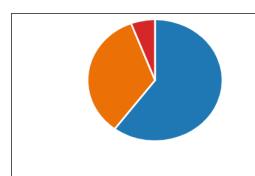
**Table 2: Age Profile** 



Of the **191** individual responses:

- **6** patients were under 16
- **5** patients were between 16-18 years old
- 39 patients were between 19-49 years
- 62 patients were between 50-69 years old
- **68** patients were 70 years old
- **11** preferred not to say

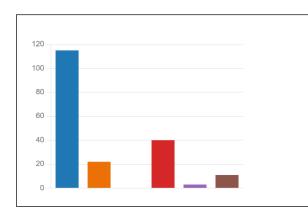
**Table 3: Gender Profile** 



of the **191** individual responses:

- 65 were male,
- **115** were female and
- **11** preferred not to say.

**Table 4: National Identity** 



Out of the **191** individual responses received:

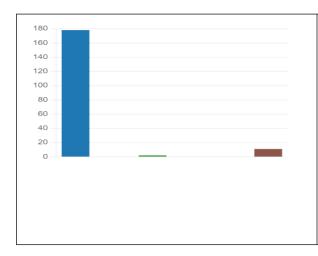
- 115 patients were Welsh,
- 22 were English,
- 40 were British,
- **3** patients advised as other
- 11 preferred not to say.

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#### **APPENDIX 1**

**Table 5: Ethnicity** 



Out of the **191 individual** responses received:-

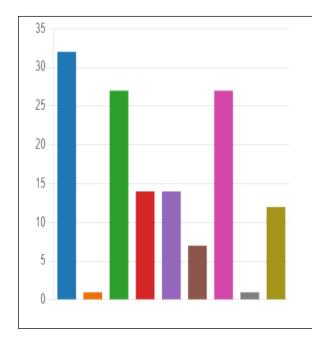
- **178** patients described themselves as White,
- 2 responses described themselves as Asian, Asian Welsh, Asian British and
- 11 preferred not to say.

#### **Post Code Reach**

Question 6 requested the respondents post code, a more granular method of testing the reach of the response. 191 responses were received.

**Table 6: Health Board Area** 

Not all respondents completed this question, 135 responses were received



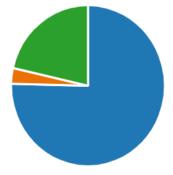
- **32** Aneurin Bevan University Health Board
- **1**Betsi Cadwaladr University Health Board
- **27** Cardiff & Vale University Health Board
- **14** Cwm Taf Morgannwg University Health Board
- **14** Hywel Dda University Health Board
- **7** Powys Teaching Health Board
- **27** Swansea Bay University Health Board
- 1 NHS England
- 12 Other

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## Understanding of how services are organised

# 8. As a result of reading this information:



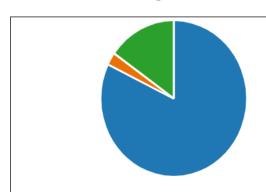
After reading, the information:

- 144 patients had a better understanding of how Bone Conduction Hearing Implants and Cochlear services are currently organised.
- **6** patients had no understanding of how the Bone

Conduction Hearing Implants and Cochlear services are currently organised and

• **41** patients understanding of the service remained the same.

#### 9. Understanding of the issues facing the service



After reading the information:

- **157** patients had a better understanding of the issues facing the service
- **5** have no understanding of the issues facing the service
- 29 patients understanding of the issues is the same

Respondents were also asked to comment on any issues facing the service.

From those that suggested that as a result of reading the document, they had a better understanding of the service, the following comments were made

If possible could we have Baha Bone Anchored Hearing Aid facilities in the Ceredigion area as travelling on a bus to Neath or Cardiff hospital would be too much for a pensioner even myself when during COVID I had to pop into A&E as I developed an infection and not one person seen one of these so thankfully I had a work colleague with me and between us was able to explain what is required but it was a struggle

I have a cochlear implant. The reorganisation of this service is necessary, to create the best service possible to give the service users the best quality of life available. I think it should all come under one central unit with all the surgeons and after care can be carried out.

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Appendix 1

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#### APPENDIX 1

The only objection I would make is the location of this unit, you have stated that you are using Cardiff as a temporary base but that is where you intend it to be. I will object to this location and I think it should be moved back the Bridgend, it is extremely difficult to travel from any part of West and Mid Wales to Cardiff by road or rail, parking is impossible, taxi fare from the station is £15 to £20, Bridgend is more central to all.

Understandably, patients want local access to services and are reluctant to travel far for those services. Similarly, the health boards also want local services but the specialist nature of the service limits the extent to which each health board can keep the service within its own boundaries.

Yes, the service offered needs to be cost effective (to obtain ongoing funding). Accessible through all stages of delivery and safe. A good robust service not a smattering.

I find the low level of patients described in this document difficult to accept.

Years ago, when my son needed his operations the waiting lists were quite long & funding was difficult. It seems better that these issues are less now.

Yes very much so. Taking away Bridgend causes so many travel problems: 1. a train & then 2. A bus. Parking at Cardiff Hospital is ridiculous and not up to standard for such a large hospital. As I am a pensioner, this means paying high train fares.

Future patients able to be referred to hearing Implant centres by their doctors or consultants for further assessments.

Would travel arrangements/costs for out of area be available?

Some patients will be less likely to opt for BAHA due to travel commitments. I struggle with a small minority of CI candidates who do not want to travel to Cardiff for an assessment. It provides a barrier to some. Otherwise, it is a good idea.

Availability of workforce. Easy access. Parking.

Personal concerns that the issues may affect my own access for any issues, concerns and follow-ups in the future. I have thus far since March 2021 had exemplary care, communication and access to the CI Team at UHW.

There are less patients with BAHAs than I expected

I am wondering if this will have a positive impact on waiting times.

Yes I do. The wait for cochlear implant was long and I had a complication after surgery, which could not be resolved by the operative time. This was very frightening indeed! The Team was not accessible, and they should have been.

Waiting times for appointments

Young persons should have priority.

The arguments are not convincing. There are movements in Wales into having things done centrally. Generally, patients like things done closer to home. The NHS is under pressure at all points. It has coped well, everywhere, with covid

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#### APPENDIX 1

No issues as such but I do think Bridgend Hospital should still be seeing patients that had their operation there with Mr Backhouse. A wonderful service and Cardiff is too far to travel to.

Centralisation - no mention of transportation arrangements.

Only issue I have is I am not seen for 12-18 months.

I was fitted with my BAHA at the QE Hospital 10+years ago in Birmingham. When I moved to South Wales in 2017, I went to Audiology at Gwent Hospital a few times for re-programming as I was experiencing problems. At this time, I had a hearing aid for my other ear. I have recently had a letter from QE Hospital Birmingham to inform me that my device is now obsolete. I have an appointment on the 27/01/2023 at Gwent Hospital to address this problem.

Sustainable hubs for outreach support model for patients needed. Many will be concerned regarding access to local facilities.

If this means that children/adults are able to be assessed and acted on more promptly, it has to be a good change. It has changed my life for the better.

Yes - waiting times are too long.

After being referred to ENT, I was initially told I did not fulfil the requirements for Cochlear Implant, was referred to the Coach Trial - who declined me and said I was eligible for Cochlear Surgery!! What a roundabout!! As soon as I saw a different ENT Surgeon everything went very smoothly.

Having a single centre for CI/BAHA is challenging, surely, for staff intervention. It's a huge catchment area, meaning travel eats into staff hours (for QTOD visiting children).

Not really, but having an implant changed my life and I am eternally grateful. THANK YOU.

ease of access and good communication with clinicians is a key issue No - just trying to make an appointment with Audiology, messages not passed on.

I am currently waiting for surgery to remove painful and swollen skin around implant - I was placed as Category 2 for surgery in September 2022. I am still waiting and currently on antibiotics for infection - it is vital I have surgery; my fear is when will this happen?

Had my BAHA operation in 1992 with Mr Phillips of The Welsh Hearing Institute. I was the 7th person to have the operation. Before COVID started, I was seen at the hospital once a year for a check-up, which I was always glad of. So I knew there was no infection with the scar in my skull. We no longer get that treatment now.

It would be a good thing if Cochlear were done in more hospitals.

I can understand it but needs some more organisation and regular dates.

To provide a more sustainable and effective service it makes sense to consolidate the main service to one area.

Long term, consistent funding is a concern, especially for training, retaining and replacing specialist staff within a multidisciplinary cochlear/audiological team.

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#### Accessibility for patients

Patients could be asked if they can make a donation towards costs. Whenever greater expenditure would create greater savings this should be looked at.

Still a very poor understanding of Hearing Impairment and Deafness within the community at large.

If this facility is too far away, how are people going to get there?

It is obviously very difficult to maintain a good service with smaller units and lack of staff and expertise.

I could understand that in smaller areas around wales, would also have a smaller amount of patients compared to a big area such as Cardiff. I do understand that in smaller areas may have less qualified specialists/doctors in the area.

I agree that having all the specialist support in one place can benefit surgical procedures and implant recipients.

More of a local service - no further than Cardiff.

Having somewhere local and tidy somewhere service as everywhere else would be a bonus. Many people have recommended this but I have a awaiting a second option in May 2023

I feel those working in this area should have at the very least basic sign language skills.

Funding for these services and location.

The cochlear implant service has been working under 'urgent temporary arrangements' for three and a half years. This could and should have been resolved by now, but putting CI and BCHI has complicated matters. These are different devices for different populations with different needs. The ongoing situation has put enormous strain on the service and staff.

The CI service has been working under temporary arrangements for a long time. This needs to be resolved as it is impacting planning and service development. There is no question that the CI service needs to be in one centralised hub, but the BCHI is not so clear-cut. Putting them both together is just prolonging the difficult situation facing the CI Service. BCHIs require a much simpler surgical procedure and provide a different way of amplifying sound, but the listening experience is essentially the same as with a conventional hearing aid. CI surgery is much more complex and carries more risks. The way sound is delivered by a CI is entirely different to a hearing aid/BCHI and patients need to learn to listen in a different way, which causes physical changes in the brain. This is why additional rehabilitation is needed. The needs of CI and BCHI patients and the services they require are very different. I'm not sure that WHSSC fully understands the differences.

The service needs to be established, as a single centre for cochlear implants in south wales - the talks of mergers has been ongoing for too long. By trying to add in Baha now against clinical judgment it is adding a complexity needlessly.

I work as a Stakeholder Lead for an NHS organisation undergoing a Transformation Programme to determine a Future Service Model. Totally appreciate all the issues facing the service and they are very relatable.

In table1 Referral's there seems to be enough numbers for cochlear implants and bone conduction hearing implants to meet the criteria for number of patients per surgeons?

Yes, we feel the service was much better previously. The Bridgend Service was fantastic.

The Bridgend Service was significantly better, providing excellent services to me and my family.

I understand more about issues facing the service

From those that stated they had no understanding of the issues facing the service, the following comments were made:

I understand more about issues facing the service

Really disappointed that the cochlear implant service was removed from the Princess of Wales Bridgend. The Heath is not easily accessible I feel like the service is being diluted and isn't as comprehensive as it used to be.

From those that felt their understanding was the same, the following comments were made:

#### Make a weekly hub

The issues described are common to many aspects of life. A centralised service provides more options but inevitably makes it slightly less convenient for customers/clients. This is analogous to the closing of rural primary schools in favour of larger schools with more facilities.

The shortage of fully trained staff and the one hospital closed is awful. We need more staff and more money to enable this much-needed work to be achieved.

If this means that children/adults are able to be assessed and acted on more promptly, it has to be a good change. It has changed my life for the better.

The lack of qualified staff for the demands. The long waiting times involved.

The Government needs to fund services better.

Enough staff is essential.

No privatisation of services should take place.

I can see the problems with staffing. Would the staff from the other hospital be employed by the Heath Hospital?

The treatment I receive is very good. Staff brilliant.

Don't sink to the standards of OA Hospital Portsmouth!

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### 10. Would you agree/disagree with the following aims for a future Cochlear Implant and Bone Conduction Hearing Implant service:

#### The service:

- can deliver a safe and sustainable hearing implant device service for the adult and children in South Wales
- has equitable access
- meets national standards
- has staff in the right place with the right specialist skills
- facilitates timely access to surgery
  - **160** patients agreed
  - **12** patients disagreed
  - **19** patients neither agreed or disagreed

Of those that agreed with the service aims, the following comments were made:

#### I have a dedicated cochlear support nurse

I personally can't fault the care and service I have received

The local service provides timely and effective care. Continuity of patient and specialist relationship is important. I am known to the service by name and not just a NHS number.

My hearing has fallen rapidly in recent years and I would assess my hearing as only being around a 5 - 10 on a scale of 100; whereas with my BAHA I would estimate my hearing to be an 85 - 95. to this end I am scared of losing my BAHA (it can easily be knocked off) and therefore, selfishly, hope that future services will be in my locality should I have some sort of problem. I know that I could not cope without the BAHA.

I have used hearing implant more than five years and I can feel better using hearing implant (Cochlear Implant System).

#### I am very happy.

If waiting lists and funding are long then the longer it takes for the person to adjust to the implants, causing further issues.

As long as I and others can get the help we need.

Fully aware of the difficult of Cochlear Service in South Wales

#### I have high confidence

Essential that the service be maintained and available as required.

It has to be accessible to all ages, socioeconomic groups.

It is a very loaded question! No-one will disagree with the premise that you wish to improve the service.

More people in one place will be better.

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The access to timely surgery would be a great outcome here. We also struggle as a small team to dedicate all the admin time to provide figures for the BCIG meetings, if this is managed by one team this would be great.

Right to have one 'Facility' for children and adults. Should make no difference.

I would like to place on record the contribution to cochlear implant hearing service made by Heidi Williams at University Hospital of Wales, Cardiff. She is an immense credit to the service..

I feel the care I've received from the CI Team at Cardiff (UHW) have achieved all the above.

Having everyone (staff) in one place makes more sense to everyone.

From a patient's perspective, all of the above 5 bullet points are vital.

There is NO service for specialist skills to remove implant for MRIC for comer patients in South Wales.

Access may be an issue as some patients and their families will have to travel further but to get excellent standards of care the service needs to be centralised

I think that this will be a positive move, everything will be easily accessible and all at one place.

Multi-disciplinary patient assessment, education, surgery details, skilfully performed implant operation, post-operative follow-ups, early and ongoing support for the implant recipient will work better.

My experience of the team at the Heath hospital has been excellent

I think this will be a positive move, everything will be easily accessible and all at one place.

The issue for those with BCHI/BAHA is how the arrangements for dealing with regular infection flare-ups is CLEARLY stated to BAHA patients, and early entry to deal with infections is paramount!

Centralising a service which serves a small number of the population allows resources to be pooled and staff to gain more experience. This also gives a fairer service and safer.

This would be a brilliant idea.

It's difficult to achieve a cost effective process balancing the needs of a small percentage of the population.

Having the facilities for adults and children under one roof would make more financial sense.

I have access to UHW which is convenient for me but many others will have travel difficulties.

Like all new ideas obviously we need to find out in practice.

By agreeing to the above wording, it suggests that the aims can be met. I would prefer 'aims to' to be added to beginning of each of the above statements rather than 'can, has, meets, has, facilitates'.

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This depends on better communication access - I had to fight for live professional captions for a remote consultation. Meeting communication needs must be a priority and not a battle!

Have doubts about equitable service from my personal experience. At my initial appointment, I immediately knew that I was not going to be referred for surgery from the consultant's attitude and apparent lack of interest. Fortunately, it all changed when I saw the ENT Cochlear Surgeon.

From my experience as a deaf person, it was important for me to have familiar staff who I knew well and trusted, therefore a more family type atmosphere, easily accessible.

See above. I am aware that the NHS is under huge pressures. Having one hospital, as a centre for surgery will surely put compromise on availability of beds.

My only problem is getting to the University of Wales due to a walking problem so I have to ask the Ambulance Service for help; they have always obliged.

Local outreach and access, including audiology appointments and rehabilitation appointments would enable ease of access

I agree with what is proposed.

Reassuring that a wider range of specialist skills would be available.

Adults should have better support and more therapy.

I would like to agree because the problem I had before my op. was that I had to wear 2 aids in my ears, the hearing aids caused a lot of infection and irritation, had to go to the hospital every week to have treatment. When I had the chance to have the op., it was great. No more infections and irritations, and a better quality of hearing.

It would be more beneficial to the MDT to be able to maintain their skills/experience and share knowledge by coming together in one location.

Currently I attend the BCHI Unit within the ENT Clinic at Cardiff University Hospital. I live near Pontypool and would NOT wish to travel further than I have to in the future.

I agree with the aims above, but would still prefer to have the services at Bridgend to reduce the need for travelling a long distance for children and the elderly.

A main (one Hub) is the way forward for a seamless approach and understanding.

My National Identity is Scottish (Scottish tick box missing on DB so I couldn't add this! Sarah J)

Having experience of having had my preoperative assessment many years ago i.e. 1996 for a cochlear implant at the old Bridgend Hospital followed by being the 1st to have the implant at the then new in 1997 Princess of Wales Hospital. I agree wholeheartedly with there being one centre with the required service listed.

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It makes sense to rationalise the service and retention of specialists. Post-implementation I would still like to see more D/deaf specialist mental health provision including counselling.

Feel the expertise would be in one place which should be a good thing.

The standard of service keeps improving and I am pleased with the service I have received.

All under one roof would be better and to see consultants quicker would be great (I have no problem with the Royal Gwent Hospital).

It makes sense to provide one central hub for patients and staff.

Whilst Cochlear Implants can benefit from one centre I'm not convinced just having one BCHI Centre is beneficial.

Hope it would give more people with hearing problems access to either implants, As Doctors, Nurses and hearing .specialist available to help.

Please assure people on their own can access appointments in a timely and not costly manner. I have to go to Bristol Eye Hospital - no appointments after 3.00 pm - or transport won't accept. The single from Bristol home is about £200! Not on a pension it isn't - I won't/can't afford it!

If everything was in a central place then standards would improve and the service provided to patients would be better.

No-one is going to argue with these aims, the argument is what services need to look like to deliver these aims.

These are common-sense aims for any service; I can't imagine that anyone is going to disagree with this in principle!

Staffing shortage with Princess of Wales Hospital Cwm Taf Morgannwg being closed

My daughter who is 4 has received outstanding care and support through the process of having her cochlear implants 2 years ago.

Of those that disagreed with the service aims:

I am concerned about the apparent travelling difficulties created by the proposal.

Centralisation doesn't work. Staff are wonderful but getting to you is not good and there's many much further away than us. If you need to save cash get rid of Managers, etc and get more nurses and doctors.

I could not agree with a proposal for one centre given the difficulties for many of your customers to travel. It is already too far for me to travel to Cardiff as it is.

Timely access to surgery: In my case, this is not happening. Category 2 patient seen by surgeon who implanted the new cochlear implant. Still waiting for surgery.

I cannot fault the service but it's a shame that I have to travel to Cardiff to be seen as they closed POW.

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Cochlear Implant Services do not need to be grouped with BAHAs. They are very different and do not require the same care pre or post operatively. Trying to merge services in this way will be of detriment to patient care. The consultation process sought the views of professionals working within the field and yet you admit in the paperwork that their clinical opinion has been ignored.

Travelling from West Wales to Cardiff is just too far. My family travelled miles to Bridgend but Cardiff is ridiculous. Why if there is to be one centre does it have to be in Cardiff? Why can't it be more central?

Residents from West Wales to Cardiff would have to make a long and often tiring journey. Bridgend is quite far already, but travelling further to Cardiff would take an entire day. A service that is located in a more central region of Wales would be ideal and accessible.

Of those that neither agreed nor disagreed with the service aims

I don't know. I have always thought, highly, of the services.

I have not seen anyone for 12-18 months so cannot agree or disagree.

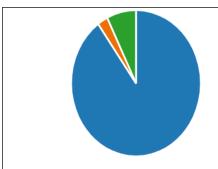
For all of the above to be achieved I think will take a long time. It needs much more funding.

Like all new ideas, obviously, we need to find out in practice.

the success of delivering the future aims is very much dependable upon consistent funding

It's hard to predict the outcome as this could be overwhelming to move into one location. I do understand that there will be more specialists at hand to do the surgeries/appointments and etc. The concern is the wait time to have these surgeries as there is now going to be a vast amount of people going into one place. I am optimistic that this would work.

## 11. As a result of reading this information, what was peoples understanding of the process that had been followed to arrive at the preferred option?



**172** Patients have an understanding of the process that has been followed to arrive at the preferred option

- **5** have no understanding of the process that has been followed to arrive at the preferred option
- 14 patients advised this was not applicable

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Of those that commented in this area:

Needs to be robust centralised service, not piecemeal.

I understand the processes but it is always best for everything to be started asap.

No what's the point you won't listen.

Easy on papers. Will it work?

My understanding is that it has been practiced and tried with a positive outcome. That will benefit patients and staff with hopefully the best outcome.

They are used to making very difficult decisions in the NHS. I can't really comment about the process followed.

Financial was a main consideration.

I do not think the needs of the patients have been prioritised, ie the need to go to a near, accessible quiet hospital.

My treatment was 100% professional and caring.

Every children and adult (if deaf) should receive a chance of both operations i.e. whatever they need.

Robust and comprehensively/clearly explained.

I believe a single unit designed to treat all BCHI patients would enable all patients and staff to concentrate on this specialist area of medical treatment.

Many people did not come forward during the pandemic to get advice about their hearing. The number could increase as time goes by, needing more operations.

I can't criticise it and I can't say no.

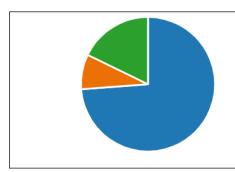
Have to consider number of CI and BC patients which are very small considering population of Wales.

Perhaps some patients could have been included in this process.

If it means that more operations can be carried out then yes it's definitely needed

The process followed appears to have been a fair consideration of the views of all parties involved.

# 12. What do you think about the preferred option of a single implantable device hub for both children and adults with an outreach support model?



- **141** respondents agreed with the preferred option
- **16** respondents disagreed with the preferred option
- **34** respondents had no particular view on the preferred option

## From those that agreed with the preferred option, the following comments were made:

It would be great for Adults and children to have one unit Nice that children and adults can communicate, can help.

I agree with this option because both Cochlear and BCHI, Bone Conduction Hearing Aids, would all be under one umbrella. With the right staff who understand how people with profound hearing loss feel, cope and deal with every day with this very real disability.

I feel centralised services would be more joined up and accountable
This sounds fantastic to have this facility all under one roof. I don't
disagree but please consider people who live in rural areas and the
valleys where I live, as transport isn't easily available especially if you
don't drive. At the moment I go to the Royal Gwent which is easy for me
and I could get a bus there. But Cardiff and further afield would be a
problem especially if you can't drive (I do drive) so please consider this
when deciding where you're going to place it.

It is good. It is better to be in one place so people know where to go. Staff will be with a specialised team. If it is in one place, it may be difficult for some people to get to. One member said she doesn't use hearing aids so she doesn't know much about them. It is a good idea to have a single implant centre. Good thing for children and adults to use the same centre. Keep the same staff as it is good to have the same nurses.

I agree, more service users would benefit

Although I understand the preferred option, I am concerned about the location and travelling further for treatment. I already travel to London for treatment that cannot be met in wales. I am struggling financially because of this, as I am not entitled to travel expenses. However, you dress this up it is a down scaling of services. I had to go to Cardiff for brain surgery as the centre at Morriston hospital was closed. I have also had to attend Cardiff for other services because they cannot be provided locally and the waiting times are longer than local and not acceptable.

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I agree that specialist services would be better served where more staff can be accommodated in one or two centres but, as explained above, hope that this is in my areas.

As the number of patients using the CI and BCHI service is relatively small it is reasonable to centralise the Inpatient aspect of the service. However, there are many of the Outpatient aspects that should be provided at a more local site to reduce the impact of travel particularly for patients living in rural areas of West and Mid Wales. For example, initial assessment with Hearing Tests, CT and MRI scans should be available locally. Similarly, post-op assessments could be carried out near to the patients' home.

I have no comment about the preferred option and I agree with the preferred option as a positive option.

All the required skill set in one place.

The professionals doing this work know what they do and know best; they are second to none.

Travelling difficulties and a possible greater inflexibility in the availability of appointments.

We need more hubs; I have no problem with children & adults being together but what next? Will we be going to Bristol next to save cash? It is biased. While less strain on services, some people find it difficult to travel and a single hub may result in people not getting the help they need. You would not have one optician for the whole country, why should ears be different?

Finance prevents more than two hubs

It is disappointing that this may cause any Implant Centre's to close with further hardship to staff and patients. I feel it is important to maintain the service in the best way possible for everyone involved.

I am not clear how the proposed change will affect me. The change to the service seems aimed at those people yet to receive an implant. So it would be better to ask them - except you can't as you don't know who they are. For myself as a patient with an existing BCHI (BAHA) I have periodic reviews and check. These currently take place in the Royal Gwent. Will this still be the case or will I need to travel further to the new central centre?

You mention a central hub. Where would this be based and at what cost to the Sennydd? Would this be part private funding? Will existing staff be prepared to move to provide same service? If not, what skill base can be retained? In the current climate within the health service, how far down the list for this vital service do you see yourselves?

The only disadvantage is the additional travelling expense where patients reside far from the hub.

I agree however, I think the location in which you choose to put the centre is very important, as it needs to be accessible to all patients.

I am currently happy with the care I receive from UHW/Cardiff but fully understand the issues with the current service. My only concerns are accessibility, communication for my own future CI journey.

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Easier for everyone to liaise & patients.

I hope this option will improve the quality of care and I also hope that I can attend a specialist closer to my home.

It is the only option to achieve the aims stated.

It would have to be in the Swansea/Bridgend area as Cardiff is too far East and with older patients and less public transport, the appointment would take a full day.

My only question is WHERE? There was nothing in the report to suggest where the new care centre will be

I have always been pleased with the service for my sister and would be willing to go wherever is convenient for the staff. We are so grateful for all their help.

Centralised services for Cochlear and Bone Conduction Implants will get together highly specialised equipment, resources and specialist expertise in one place. This is a recognised model of delivery highly specialised services to relatively small number of patients, but all of the recipients have got a new lease of life! I would like to benefit from more timely resolution of problems - technical and clinical. A centralised service will have better connections with the industry and more timely upgrades of process and novelties. It is necessary to have accurate information as to who and how to call with any problems and the response service to have a patient advisor present.

Where will the hub be? It must be easily accessible by public transport as well as by car. Will there be dedicated parking spaces for clinic/surgery attendances? Will attendance times take travel distance into account?

Only concern is transportation for non-drivers, low income/elderly

Better to have a central team at one location

Cochlear Implant Clinic needs to be more Central Cardiff - is too far East for most people.

My concern will be accessibility for patients who will have further to travel. Will the additional travel costs be funded? I agree with idea of all services under one roof but will this lead to staff being made redundant?

I have the Cochlear Implant and I became independent since they gave me the implant. I used to be dependent on other people. I know it would be better for every patient to get better services and support for South East and South West Wales and South Powys. I also agree that a single centre would be better and able to provide a high quality service too. At present the hospital service is not able to provide good quality service due to the NHS funding cuts.

As an implanted adult I am happy to continue with the service from Cardiff Heath Hospital.

I think it will make more sense than in the previous options, it will be able to budget and also allow/include the much needed help that will be offered with this new option.

Whilst I agree, the clear arrangements for self-referral for ear infections (BAHA) MUST be made to patients as they will probably be life-long clients.

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I agree and understand why services need to be centralised, for financial reasons and also the usage of services by the clients. I visit Cardiff University Hospital and have been for over 25 years even though I live in Carmarthenshire. I do have a worry of integrating children and adults in the one hub/department unless appointments are staggered.

In an ideal world with money no-object a number of centres is the answer. I can understand that for some people travelling further can be difficult but to access this excellent service we should be prepared to pay additionally towards it. Maybe there could be some funding provided for travelling for patients who would struggle to meet the costs.

The outreach support model in Neath Port Talbot will be accessible to myself.

Preferred Option: I would hope that it will be sustainable to fund the change of staff to implement this preferred option.

I understand the need for a single implantable device hub for children and adults with an outreach support model but am concerned at the level of service that will be provided having experienced a deterioration as a consequence of moving from Bridgend to UHW.

Whilst I agree that a single centre is best, I would want to see NO reduction in staffing resource by centralising. We have seen that centralising other services has worsened service. If the same full time equivalent resource is centralised then it may work. Ideally, I want more time available for CI mapping and enquiries.

Although the preferred option appears to be the most suitable, until I know where the Main Hub will be situated, it is difficult to pass a comment.

One Hub will make travel harder for patients.

I can only say how it changed my life to be able to hear again and to be able to speak to some people on the telephone.

Easier access, locally provision of service, less travel to the centre which can be difficult for some patients, may encourage improved joint working and knowledge of the implants amongst local health board services

I agree that after service of the BAHA in local hospitals or local surgeries are a good thing for transport costs and convenient for patients.

Although it may be useful to have this you would have to think about whether it would have an effect on the surrounding communities.

I agree one place does everything for deaf people.

The most important thing is the experience of the person setting up the hearing aid to give maximum benefit. If you have to travel for this it is worth it.

As long as it provides a first class service to all - and completes necessary operations in expected time scales.

Although I do agree with the preferred option and its supporting arguments, I do find it disappointing that as it is all centred in one place then it will obviously have a significant impact on travelling time for many people.

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Neath Port Talbot ENT has been and still is a very good clinic, and I hope it will continue to be the clinic that I can attend.

Children need both implants in order to develop their speech.

As I have BAHA fitted I know the value. I had my BAHA fitted over 11 years ago when I lived in Barnsley. When in Barnsley I only had to attend 1 hospital for all ENT. But since moving back to Wales I've got to go to the Heath for BAHA, Llwynypia for Audiology and ear cleaning. When I first moved back I had to go to Mountain Ash for ear cleaning which meant I was attending 3 hospitals.

I think it's better to have Option B.

The effectiveness and efficiency delivery of the preferred option is dependent upon the availability of specialist staff

Any future upgrades in technology and or surgical methods can be practised at this hub.

A single hub would streamline the problems faced by all patients with various/different levels of hearing loss. All patients and staff would only be focussing on deafness leading to a superior service than is currently available.

Accountable, joined up, patient focussed.

If there were enough referrals and enough staff, Bridgend would be my choice to continue to have the 2 hospitals giving a service to hard of hearing children and Adults.

As stated above and cost effective service will maximise professionalism. A "Centre of Excellence" in Cardiff.

If I may be so bold as to give my personal view on the location of a central Hospital, then The Princess of Wales Hospital in Bridgend would be my choice. Clients living in Pembrokeshire or even the rural areas of Carmarthenshire find it quite stressful driving so far east to Cardiff.

My BAHA was fitted in Birmingham so I have no experience of the implant service in this region. A single hub for the surgery and implants seems a sensible idea. If the ongoing support remains in the same place as now, then there will be no change for where I access my audiologist. Having most appointments closer to home is better for most people.

I think it's a good idea to have all the right staff and experience in one location instead of being spread between several sites. This would benefit peoples' aftercare and when the patient needs advice on any problems that may occur. Cost of one location would be easier and reduce travel costs for staff between sites.

Understand the need of people having to travel to centers. Make it easier for rural patients and for those who find access to one center difficult. It could be done.

A single center at Cardiff would suit me as I live close by.

I think all the proposals and actions are ok.

It would be a good idea to the BCHI and Cochlear Implant Services in one hospital, but I can drive!

Any change for the deaf and hard of hearing would be amazing! The BAHA team do amazing work and to have a unit would be a great help to

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the team and patients. The difference the NAHA service has made to my life was that I can still work and enjoy life and not live in the "quiet world" feeling patronized. There is still a long way to go for a better understanding of the effects of loss of hearing and disability. Mr Williams and his team do amazing work, it transforms lives. So anything that can benefit research, funding and a specialist unit would get my support and am available if you need a "voice" to help.

I believe this would make the service more of a nucleus for the S Wales area and consolidate the skills of hearing/audiologists/D/deaf specialists across this part of NHS Wales. By bringing staff and expertise together, better care can be practiced. A trained and responsive Outreach service at local audiologist deaf units would enhance the hub. This is very important especially as someone who was referred by an audiologist with strong knowledge of Cochlear Implants.

I agree with the option if this means more patients can be seen. Would it mean an enlargement of unit at the Heath to accommodate extra staff/patients? Hopefully more cost effective. Would there be more outreach units?

No proper instructions on how to use the kit provided. I am 84 and my wife who has a Cochlear Implant is 83. And so getting to the Heath Hospital would be very testing. It is also hard by telephone to get to the Cochlear Department to order spares to batteries.

I understand the issues the services are facing. I do agree that it should be moved into one location. My main worry is that the wait time to have the appointments and surgeries may be longer. As stated before in the survey, it already took 8 weeks for an adult to be seen for a referral? This fact is based on the hospital in Cardiff, the highest population in Wales. This could take much longer now as more patients are going to one location. Although the Activity rate should now be increased which would be the positive.

I am very sorry that the unit at Bridgend is closed. As a person who has been deaf for many years my confidence levels was very low and I become reluctant to attend medical appointments. However, the small group was friendly and warm I was immediately put at ease and was happy and relaxed throughout the procedure and actually looked forward to the visits. The hospital was easy to get to and parking was not a problem. I have found the opposite to be true of Cardiff, it is extremely busy hospital where you have to wait to be seen for a long time. It's impossible to park and have to drive out of the hospital grounds and park on the roads outside. I am confined to a wheelchair and makes life very difficult.

I had my CI in March 2021 during the pandemic at UHW. From the first consultation I was received by a great team of highly trained and professionals individuals who helped me make my decision into accepting CI which was done 3 months after my evaluation and clinical decision making appointments. UHW is easily accessible for me although I live 34 miles away, parking is a nightmare. i have had amazing support from all

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of the CI team at Cardiff and hope that will continue in the future, wherever you decide to base the unit.

If it means more staff and more people having the op. Yes I'm all for it they are just wonderful at the UHW Cardiff but transport getting to the hospital not everyone has a car but having one place makes sense.

I agree if there is a single center they will provide a high quality service but in my experience they need to have regular dates and appointments. My sons appointments were cancelled several times and one of the reasons was because they were short staffed in a "big hospital"

I do think this is a great idea especially if it helps people get the quality care they need and a shorter waiting time will be helpful for many patients.

Having one team of skilled experienced specialists in one hub can be a huge benefit to implant surgery. It is however vital that regional outreach support is maintained as access from across Wales to one central hub is not practical for all.

Suitably trained staff and facilities at one location.

I think it will make referrals easier and give a more equitable service On the basis that the central service provides enhanced care then this can only be a positive step.

I agree that it would be beneficial if there was a centre of excellence. My concern would be location as the area covered in these proposals would mean travelling when transport is not the most reliable without a car.

OK but note my comments i.e. Welsh Ambulance times! I'm on my own, as many older people will be; transport in a taxi is beyond my means. No public transport. Even the community transport costs are beyond my means. QA Portsmouth did my surgery & was left in a ward under the care of my aunt for 5 hours! Aftercare didn't exist. Lost my Notes, refused even to remove my stitches. No follow-up. Now they tell Cardiff (excellent treatment) that I never existed! I had different hearing tests by default at QA. I could hear noise though not words properly. Now have a BAHA fitted though no ear chords - bent over.

By having everything in one place ensures that staff are trained to the highest standard and that patients can access everything in one place without the possibility of "falling through the cracks". Patients will know exactly where to go if they have questions or need advice. However, I do believe that follow up is important. After having my BAHA fitted last year I have had one follow up and that's it. I feel like I have been left to my own devices now. It would have been helpful to talk to other people who have an implant for support and real life advice afterwards. I do believe that patients would benefit a lot from being part of a community before and after the surgery and not just left to "get on with things"

Alongside the changes proposed we suggest some families will face additional time and financial costs associated with travel into Cardiff. Whilst some may be entitled to a travel reimbursement, they will still be required to fund the up-front costs associated with the journey. Additionally, for some families, the appointments will require a full day

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away from school / work and this may negatively affect patient experience. Any unforeseen problems arising from surgery will not be dealt with locally; therefore, some families may be required to commit to additional journeys to receive the right care and support. Investment to support communication from the host site to local services will likely be required to ensure local service systems can be automatically updated. Families' emotional needs should be considered in these proposals and responded to as appropriate.

I agree that a single hub is appropriate for CI. I do not think it is necessary for BCHI, although it depends what exactly the proposal is. A centralised MDT could be helpful, but it is unnecessary to make patients travel large distances for such a simple surgical procedure.

I do not think it necessary for all BCHI surgeries to be carried out in one hospital. The team who 'independently' assessed the situation and recommended one hub for BCHIs do not even run their own service this way, with surgeries carried out in several hospitals.

From our perspective we already feel that we are part of a single hub set up.

It is better to have all staff in one place instead of having to bounce around hospitals. However it must be central and easily accessible.

I think that by having a single hub you will have access to specialist surgeons and better facilities to better help patients.

As stated the preferred option is not the preferred option of those working in the field with clinical knowledge of the needs of the service. Please reconsider with this pertinent information in mind.

1. Would provide a service with an equitable level of quality and standards across Wales. 2. Would have the same level of governance and accountability. 3. Sustainable - if the financial appraisal has shown Option D to be most cost effective. 4. Opportunities for service development along with technological development. Negative: Socio-economic issues with increased travel times and potential lack of local engagement to CI and BCHI users who may be negatively impacted by loss of local hubs.

'High volume surgical sites' are key for good outcomes. At the same time follow up services should be 'local to a patient' for better compliance & outcomes

Because waiting times would hopefully improve and staff shortages decrease

From those that disagreed with the preferred option, the following comments were made:

Preferred Option: A single device hub ensures and maintains professional input & status, and the outreach support enables access for all service users. It prevents a watering down of the service.

I agree mainly because I think it is very important to employ and keep the highly qualified staff necessary for the service to be provided.

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I think if we could converse/relay our problems to an accessible Audiologist quickly it would take away some of the panic one seems to suffer if we have a problem with our aid. Because it is such a life dependency item. Also a specialised hub would be solely beneficial for us patients. I actually waited 7 years in between my upgrade of my aid.

Too large, anonymous, patients are not familiar with staff and feel insecure and apprehensive. Harder for relatives to visit.

I agree because there are specialists who know their job. So I believe they will make the right decision on a preferred option.

I also agree with Option E as well as Option D. Option D appears to be better than Option E because it has an outreach support model.

I had a cochlear implant at the Heath Hospital in Cardiff (deferred from Bridgend). As I live in South Pembrokeshire it was a long way to travel. However, the benefit of having the Implant far outweighs problems of distance. Help towards travel expenses is available from the NHS if needed.

I would rather have an Adult Hub separate from children.

It is an unnecessary complication to include bone conduction devices. Not all bone conduction hearing aids require surgery yet have similar requirements for follow up and serve a similar population. The follow up required for Cochlear implants is significantly different, requiring users to adapt to an electronic rather than an acoustic signal.

No matter where in Wales the hub is. The travel is a small price for me personally to pay to receive my care.

I consider the change in service to be prudent and the only sensible option

Financially better to have adults and children together to keep the service going. Better qualified staff with the skills that are needed, and more implants can be offered to people who need them.

It would all depend on where the centre is based. At present some of my patients refuse to travel from NHH to RGH so if it's based in the Heath or Bridgend I think a lot of my patients may decline BAHA.

I have been a user of cochlear implants for the last 27 years. I would agree I have had regular appointments with consultants, surgeons and audiology. My only concern going forward is for follow up procedures when things go wrong as a user we heavily rely on them and without them we simply lose confidence, can't join in, have difficulty at work and can be stressful.

Where do you propose to locate the single hub?

No option

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#### Respondents were asked to comment on the following question 'What do you think the impact of the preferred option would be?'

Again the Heath Hospital has been absolutely amazing ever since I was 4 years old and have always been looked after but now I have moved and would love this facility in the Bronglais Hospital in Aberystwyth as the staff there are amazing and help

As long as it is not in Cardiff a lot of users would benefit, people including myself would be put off with hassle day trips to Cardiff

Impact will be longer travelling, local services will become less patient specific. Waiting times would increase due to everyone treated in one place. Less opportunity for consultants and other medical staff to progress locally and opportunities only available in large centres.

It will leave more travelling for many patients but, ultimately, give a more specialist service and save NHS costs, which can be applied to provision of an even better service.

The quality of the service will be enhanced. Providing outpatient assessments at outreach sites will minimise the impact of inconvenience of travel.

It will be better than before. I am more interested in the Cochlear Implant System than the other old hearing aid.

Hopefully more people would have access to the service or be referred to the service at the appropriate time (I wish I had been referred 30 years earlier). Hopefully the preferred option would provide more awareness medically and within the community, therefore obtaining professional status.

Minimal impact for me. Improved specialism/consistency of service. Job well done.

Probably not much for me as an individual patient but difficulties for other patients. Thank you for seeking my opinion.

Minor inconvenience for some people, but fairly small number of people affected and most will just be grateful of the opportunity to have cochlear, etc.

I do feel that when patients are separated into children and adults, staff can maybe specialise more easily.

I don't know to be honest and I don't think you do either. Only hope service doesn't suffer as this means we suffer. Employing more nurses on better pay & conditions will improve the service. Less pen pushers. Also bring back Matrons and get rid of Managers.

A lot of people not getting the help they require.

People living in far reaches of the area that provides hearing devices have a hard time reaching one hub, especially in inclement weather

1/ Cause distress and expense for patients who will be required to travel further for all appointments. 2/ Patients referral to be assessed for an implant at a centre living further away may be impacted. 3/ Will training skills for all staff in all areas be maintained at present levels. 4/ Will aftercare following implant and switch-on be affected.

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Accessibility is the key problem for me, already having issues with train strikes, limited timetables for all public transport.

1. Hopefully the service will be better as the surgeons will do more procedures and hence gain more experience. The associated equipment should also be better. 2. In general patients will have to travel further. Nothing much you can do about that although maybe some consultations could be done remotely, although clearly not hearing tests. Maybe some assistance with travel could be provided.

Hope better service and regular check ups

I think it will impact patients in a beneficial way in most senses, however I believe they will want all their care closer to home.

I think it would have positive outcomes

Good if it works. Lot of work ahead though. Continuity of staff. To us they are friends. Easier parking than the Heath Hospital. More help needed to those living along to use new devices, etc. Particularly the older element.

Quicker response, better service, skilled staff. I received my implant 12 years ago. Everything went smoothly and I am very grateful to all the staff involved. However, after my operation, I was put on a general ward, which was very difficult for the staff and myself.

Sincerely hoping that you will be able to maintain and offer the high levels of access, communication and care I currently receive at UHW/Cardiff. Benefits of relocation may be easier access, ie parking or access by Public Transport, though doubt that's achievable or realistic for many of your patients. Hoping you keep your current highly trained staff.

So much better for patients to be in one place, we all have different needs, therefore if all specialists are in one place, it would be so much easier all round. It's just a shame Mid Wales is forgotten and it takes 3 hours to get to my hospital appointments one way.

More centralised services would mean that specialist teams would have a better opportunity to maintain their skills and would mean that finances don't have to be split across a number of services; therefore would be more beneficial from a financial perspective.

I feel the service would become more robust ensuring the correct staff are seeing patients

At present I'm seen in Neath Port Talbot Hospital and this is very difficult for me to get to. I would very much prefer to be seen in Singleton Hospital as I did a few years ago as I can get there much easier. I live in Pontarddulais Swansea and if there is a centre for hearing loss closer to my home and on a bus route, that would be much easier for me.

Although the desired level of service should be assured, the main impact will be on patients who have increased distance to travel for appointments and surgery. For some this may discourage them from attending.

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I would need details on the location of the single hub before I could answer. Cardiff would be my preference.

It will impact those who live furthest away, might I suggest having extra facilities available for families to stay overnight?

Better continuity of care provided. I do worry about access as living in Swansea and coming to Cardiff has sometimes proved difficult especially on surgery day as we had to find a hotel, etc. The whole Team were nothing short of amazing and the care I received was second to none. By pulling all the services together, it can only improve.

I think it will make more sense than the previous options. It will be able to keep to budget and also allow included the much needed help that will be offered with this new option.

Faster turnover of patients' appointments, less frequent technical issues during clinical appointments. The personnel is likely to be more involved in patient's care and outcomes in comparison to the service "borrowing" personnel from outpatients' departments of general hospital. I believe such service will be able to arrange timely and expertly dealing with emergencies. It can be the hub for training health professionals. It can develop research unit. It can facilitate patients' support groups, further education and training in using the implants for improved quality of life of the recipients. A Centralised Unit will measure up very favourably with other UK and International Units. I have benefitted tremendously from the skills and professional expertise of UHW Cochlear Implant Service. I cannot praise them highly enough for the years of support I have received. I believe that the Cochlear and Bone Conduction Implant Services in Wales have got a bright future and should be supported throughout.

More difficult for those living at some distance. But a 'Centre of Excellence' is certainly a preferred way forward. Outreach support must be fully supported and not just pay lip service to the idea. Staff must be fully trained and supervised to a high standard wherever they are based.

Essential to enable all patients to take their places in society with no exclusions for any person's disabilities.

probably a better service, although the current arrangements are excellent

Potential for a more complete service. Longer and more expensive travel for some people. Will staff have to relocate?

I want a good service for everyone who has hearing issues. At this moment there's not much available and it is very difficult to get help and support.

A personal view: I am 85 next month. I was fitted with a BAHA in 2008 at Singleton Hospital. The hearing loss, in the meantime, has been considerable and it is a chronic disease. The Baha does very little for me now but I can't do without it as it does pick up a level of noise. I appreciate the good work that went into getting one of those. I attend Audiology at Carmarthen Hospital every 3 months, or did pre-covid. A local centre would be nice where the BAHA could be serviced or

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replaced. As far as I am concerned, it could be Option A still with as you describe on page 19: "Can be delivered through an outreach model closer to home". At my age, the closer to home things are the better. COVID has made us a lot more hesitant about going to busy places. I think the current system is good. Then, there are your groups claiming it could be improved. Despite best attention, I have lost my hearing. There were problems from a very early age. We were in London for 38 years and had regular appointments at Ilford and Whipps Cross Hospital for treatment. We moved here 20 years ago and the transition to Carmarthen and Singleton Hospitals was seamless. The hearing loss has been dramatic. It is as if the nerve endings have eroded away and there is nothing there to work on. There is an impact on our daily lives, of course. It throws a huge burden on my wife, who has to deal with all those day to day things in our lives. She jots things down for me, rather than try to communicate verbally. I wish I could pull my weight and do a share.

It would be a lot better as you are able to see the same people (surgeons and audiologists) whenever you have an appointment, so that you can build up a patient/Doctor relationship that most people like myself miss.

Centralisation = Centre of Excellence. Retain qualified staff, maintain Dr numbers and allow cover therein. Possibility for innovation. Transport arrangements would prove difficult for more people.

I agree as it gives a fairer and safer service for patients; it will no longer be a 'postcode lottery' as to how quickly and effectively a patient is seen. Largely positive, however, it could mean transport difficulties for some patients. Also, I am assuming the service would require fewer specialists going forward and whilst this may be a cost saving, it will mean there may be losses for the staff involved. Also, would current staff relocate, or would it result in staff shortages as it is a specialist area. I want to know whether the Doctors would still have a working partnership with Paediatric Plastics in Swansea Bay (Morriston) to accommodate BCHI and ear reconstruction to happen at the same time.

Hopefully it will improve services for the clients.

It would be very worthwhile building a specialised hospital where it would enable a high end patient care ad understanding. All Doctors and their Team in a central place would benefit everyone, creating more jobs, more specialised care.

You can never please everyone, but this appears to be the most sustainable option.

A far more accessible and specialised service for both the health providers and the patients

Staff moving to central hub and patients' concerns regarding appointments. Difficult to travel to. I myself had a very good experience with very helpful and professional staff when I had my Cochlear Implant. I'm sure it should be a big improvement, mostly to relay any problem that us current users face. It can only be a good thing if children/adults

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who need help with the hearing problems are sorted quickly. I'm lucky enough to have had a BCHI (BAHA) at Singleton almost 30 years ago. Wish it was available when I was a child/teen. So pleased for children today [to be able to receive this Aid].

A poorer service. Increased costs for families living in West Wales. Increased travelling times. Whilst this is couched as a 'consultation', I believe the decision has already been taken.

I worry it will be an excuse to cut overall staffing - if this happens, no progress will be made. I am now in year 2 since my CI. I believe not enough time is given to mapping - as a result, my confidence has eroded as my CI experience has declined through mapping being done in a rush.

The following problems could arise for many people: 1. Distance they will have to travel; 2. If no car available; 3. What will be the bus service to the location. West Wales patients may have a tremendous distance to travel if the hub is situated in Cardiff for example. The principle in respect of expertise and staff levels is good. But at what price to patients? At present, Swansea, Cardiff and Newport Hubs means patients travelling. Could be more suitable and less distances involved.

I find it hard enough to travel to your centres as they are - one centre would be too much.

There will be an impact for both staff and families, particularly for areas further afield. Putting all your eggs into one basket as it were?

If my experience is that a change would be not needed to improve the service and attention I received when I was attended to. Thank you.

Better service access, knowledge imparted and improved links with local services, especially audiology teams, (if outreach audiology appointments), a possible increase in the number of people being referred/ considering implants, consistent approach

It would not be dire that is for certain but overall unsure. I was unaware that these services were in such a mess and would agree having these services centralised but not affecting people is a good idea.

I currently have BAHA 6 Power. Struggling to get settings correct which can be common from comments on Facebook Group. Would be difficult and I imagine patients would persevere less if they had longer to travel. Would you still be able to have settings adjusted locally? This would be important to me. Do you offer the Osia 2?

1. Would have more in-depth skills in one centre. 2. Would provide more consistent appointment fixtures as there would be more specialists on hand to cover unexpected absences. 3. Unfortunately, would mean significant number of people might have a significant increase in travelling time and therefore additional cost, as well as travel stress.

It would be ideal, if you could provide enough support for Adults, as children get plenty of support and therapy. But I was so struggling on my own. It took time for me to get used to it. Important to ask adults what they do seek from you and give your options of support to adults. Also, staff need to learn basic BSL, just in case. And especially reception

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staff are awful. They look down at the system whilst talking to us. How rude.

Better all round. Makes sense to keep both sections in one main centre with Outreach Support.

Whichever the option, some patients are going to travel further.

Think it would impact patients as there have been too many changes already. People want to be seen where they have been seen in the past! Improved individualised care.

I think the impact would be to go for Option B.

A more timely service with waiting times equal for all areas. Whereas now, it varies greatly between the health boards. I have been fortunate to have been treated at The Royal Gwent Hospital and had a BAHA fitted in 2018. I have received excellent care and any issues I am able to access the Audiologists within their department. Only this week I asked for an appointment as experiencing feedback issues. I have been referred back to my ENT Consultant as the abutment made needed to be replaced by a longer one. I have also been given an appointment for a hearing test as last one was 3 years ago. This is to see if I would benefit from the newer version of the BAHA, funding permitting. I am a Nurse Manager working at the Royal Gwent and am very appreciative of the care and treatment I have received. The BAHA has transformed my hearing problems. I would be more than happy to travel to a central hub with follow ups locally.

Yes for clinical reasons it makes sense but not sure if patients would agree

Distance from hub and travel time for patients will be concerning and could be problematic. May result in an increase of patients not attending.

The impact on some would include, increased travelling cost and time. But having said that as a BAHA wearer, the positive impact of having this aid, far outweighs any negatives of slight upheaval of having to travel a little further or taking a day of work instead of say half a day.

Waiting lists would be reduced. GP's would know exactly where a patient would need to be referred. Staff would not be called away to cover other areas - this does happen in multi-disciplinary hospitals/clinics. Improved communication between patients and staff. Allow for longer consultations. Better understanding of complications following cochlear implants. Patients would know exactly where and who to contact should problems arise. Overall a single centre to deal with BCHI simplified referral, consultation, surgery and all future necessary follow-ups which are essential. Adequate parking.

Improved individual patient care.

Congestion in the Heath Hospital making waiting and travelling a problem. Parking in Cardiff is always a problem. Allowing time for catching buses for people from far away could cause stress. Staff shortages causing congestion of patients waiting for attention. Too many

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operations for the surgeons to perform. Too many people waiting to be seen.

I support Option D. If that is the preferred option I think the impact would be best. An outreach support model would then be available for everyone, whenever necessary.

To enhance the lives of people with profound hearing loss. More public awareness by being a centralised approach for Wales. A hub for excellence.

For myself I would simply like a conversation regarding the problems I have with my BAHA. An expert whose input I would value.

A one stop 'SHOP' - all in one place. Great!

For me personally, no impact.

Is there any plan to make more use of digital support for follow up care? I have managed very well with my implants using headsets and Bluetooth. More training will be required for both patients and staff on this.

People might have trouble getting to the hospitals and parking is always a nightmare. Help to set up appointments would be helpful.

If the hospital is long way for some patients to get there without a car it could be a big deal for them. I live in the valleys and buses from our village only run every 2 hours and stop at certain times, so for someone without a car would be a big deal unless a transport service was made available for them.

There needs to be more help and understanding of the deaf community and maybe a complete unit dedicated to this would be an asset

Firstly I wouldn't want there to be an impact on the workforce's work/life balance by having to change work place by excessive commuting, etc. This needs to be managed sensibly. Having previously been a patient at West of England Cochlear Implant Programme, I felt at ease and safe in their care. Larger travelling distances for patients might be an issue, but with good care, long travel shouldn't be consistently necessary postimplant. Good workforce/patient relationships should be maintained if a single hub is the option. Some patients may be too used to the current set-up.

A better and quicker service while some of us have to travel further. I think it will be better for us in the long term, with all the right staff and facilities in the right place.

All things considered, it would benefit everyone who needs assisted hearing aids which are essential, as I for one am very grateful for mine. I think if it makes the process easier I'm all for it.

Benefit for all - staff and patients alike. Increase in referrals. Especially important for children as early diagnosis and help is vital. Having been profoundly deaf I consider my Cochlear Implant to be a "Miracle". Any improvement in the future provision of Cochlear and BCHI is to be welcomed. PS: Many thanks to the Cochlear Team at the Heath Hospital! To make it easier and more accessible for everyone.

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As stated earlier, I think there would be an increased amount of patients heading to one location which in turn will have an increase of wait time is the main concern of mine. I do think the positives is that financially, it could all go into one hospital which would be able to cater for all departments.

Having to travel to a central hub may put some people off having the surgery which would be a great loss to patients of the absolutely massive benefits of an implant (it changed my life for the better by an enormous amount). So the correct support may be required even providing accommodation for the accompanying relative if needed. For the surgical procedure, an overnight stay in hospital.

Would it still be the personal service I have now? I have already moved from Bridgend with no choice or option. Cardiff has been very good to me. A service that I have quick access to if I have a problem with my cochlear implant.

Fewer staff & facilities offering higher level of service to patients. Patients having to travel further for treatment etc.

i think it will result in some patients have if to travel further , but they would be seeing a more experienced team

The centre would have to be child friendly. As a child growing up we had a special Ear, Nose and Throat hospital which catered for children so the environment was welcoming and friendly.

It won't be good for many distance-wise. I can drive to Cardiff; I would NOT drive to Newport. If the new service is as good as Cardiff - fantastic. Met a lady working in Tesco - she is over the moon. Saw a little boy with an implant and showed him mine - he was thrilled. It's a good thing to mix children & adults. Let's hope many more will benefit, especially for surgery not to be in a mixed surgical environment. I heard something about teaching the children to speak with 'normal tones', including regional accents, and not sound flat. Fantastic. I just wish I could hear 'the split' and therefore learn to speak Welsh! (Being old doesn't help). Good luck. When I eventually got mine, I cried when I heard birds sing! My (name) said it was selective hearing and bad hygiene - I was 24/7 carer to my Mum. Please teach GP's. From my experience in Wales it's better - but it's so so important. I was also refused access to a hearing dog! Thank you for my treatment this past 9-10 years.

The impact should be better support for those with hearing loss. Support to access doctors who use BSL, access to the Deaf community, and a community of those with implants. A follow up to check on quality of life/ what benefit they have had from the implant would be easy to do. Staff could be trained to higher standards if they are specialising and they would come to know the difficulties facing the patients better.

In response to increased travel, time, and financial costs for some families, it will be imperative to monitor equality of access to the specialist provision once available via a single site, adjusting policy continuously to support families access as appropriate.

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Continued investments to ensure effective communications between local systems and the host database systems should be considered. We expect the related services to comply with nationally developed standards. National Deaf Children's Society works with government agencies and professional groups in developing good practice guidance and quality standards that reflect the views of parents and young people.

We suggest consideration is given to supporting the emotional needs of families opting for implant assessment, procedure, and follow-on care, which is reflected in policy, pathways and practice.

A positive development for the CI service, formalising the current arrangement and enabling the service to move forward. A centralised MDT could be helpful for BCHI, making things more co-ordinated and potentially leading to more people receiving BCHI. However, it could also be detrimental to patients if care is unnecessarily moved away from their local area.

Positive for the CI service, removing uncertainty and allowing the service to move forward. For BCHIs, it will mean that patients will need to travel further for a simple surgical procedure, for no good reason.

The impact would potentially be minimal for us as currently we only attend appointments annually however we appreciate there could be an impact for others.

More convenience and better quality treatment.

Travelling will be a problem for some people.

It was hard to adapt when I used hearing aids. I didn't wait a long time for mine.

I think it's a good idea to have in one hospital. It is a good idea for both adults and children to be in one hospital.

It will be easier for all the staff to be in one place.

My house mate wears a hearing aid; you put it in your ear.

3 hospitals to be put into one is not enough.

Travelling too far.

It can be a long way to travel.

It could be a good idea to ease pressure on emergencies. It's a good idea for adults and children in one place. It may be easier to employ staff.

It is likely that fewer patients will benefit from bone conduction devices if a central referral is required.

Detriment to the service provided to both CI and BAHA patients. The needs of patients is not equitable and trying to lump them together will not be in the best interests of the service.

Personally little impact. Potential however, for other service users to feel that there may be: 1.a lack of local support; 2. financial detriment to attend appointments. 3. Feeling of inequality due to location. 4. It would end in essence 'postcode' lottery - not in terms of treatment or expertise but would ensure consistency. 5. There would be a decrease in staff pool for the services provided. This would mean potential staffing issues

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should you have retirement/relocation of staff. It would become an extremely specialised service. It will unfortunately mean some staff would also become de-skilled.

A better, more integrated service for children and adults.

An improved service and a higher skilled workforce

enough patients seen to ensure staff skills are adequate

This would depend on the strength of the outreach support model. Visiting Cardiff from West Wales is a big undertaking - can you imagine doing this with a newly implanted Aid on public transport? If the outreach centre was located in an appropriate location then it may be considered more desirable. Also if you have transport the parking at Cardiff is horrendous. I think that people would miss appointments and feel dread at the thought of going to a big impersonal centre. At Bridgend we were known to staff and made to feel welcome and the service was second to none. The hospital was easy to get to with adequate parking. At the moment with one centre it feels impersonal and rushed. The staff seem rushed and there is little time for the care I feel should be provided for such an important part of my life. I think the impact would be very negative and with the number of adults and children with implants increasing it seems illogical to decrease the service - which I feel is already not as good as it was.

I somewhat agree but there are areas to be considered such as the location of the model. As mentioned previously, the location should be more central, such as Carmarthenshire, thus meaning more people have access to facilities. Parking would need to be of a decent quality. Cardiff has poor parking. In addition, public transport would need to be considered, as not all people with cochlear implants or have an implanted child are able to drive. One singular centre would possibly fail to provide efficient facilities and support and time - especially to newly implanted people and their families. I believe going ahead would be a mistake due to the extensive journey which in my experience is very tiring, as well as the tuning sessions being exhausting - adding hours of travel into the mix amplifies my sheer exhaustion. In addition the system feels very rushed, like patients are tasks to complete instead of people. Growing up, Bridgend was personal to me. I recall being greeted, updating staff on my life and felt more than a list. Taking the next step could discourage people from choosing to be implanted as they will have to take constant tests at the hospital in the immediate aftermath of the surgery and the activation of the implant. Prior to taking the next step, I strongly believe consultation with patients and their families would be ideal as relying solely on data and financial costs would be a severe mistake.

care will improve

A quicker response rate to ongoing needs for children

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





# APPENDIX 2 THEMATIC ANALYSIS OF RESPONSES ENGAGEMENT ON FUTURE PROVISION OF COCHLEAR AND BONE CONDUCTION HEARING IMPLANTS FOR SOUTH EAST WALES, SOUTH WEST WALES, & SOUTH POWYS



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## COMMENTS FROM THE RESPONSES PRESENTED WITHIN THEMES SUPPORT FOR PROPOSED CHANGE

Support for change	I have a cochlear implant. The reorganisation of this service is necessary, to create the best service possible to give the service users the best quality of life available. I think it should all come under one central unit with all the surgeons and after care can be carried out.
Support for change	If this means that children/adults are able to be assessed and acted on more promptly, it has to be a good change. It has changed my life for the better.
Support for change	Yes - waiting times are too long.
Support for change	To provide a more sustainable and effective service it makes sense to consolidate the main service to one area.
Support for change	It is obviously very difficult to maintain a good service with smaller units and lack of staff and expertise.
Support for change	I agree that having all the specialist support in one place can benefit surgical procedures and implant recipients.
Support for change	If this means that children/adults are able to be assessed and acted on more promptly, it has to be a good change. It has changed my life for the better.
Support for change	More people in one place will be better.
Support for change	Right to have one 'Facility' for children and adults. Should make no difference.
Support for change	Having everyone (staff) in one place makes more sense to everyone.
Support for change	I think that this will be a positive move, everything will be easily accessible and all at one place.
Support for change	Multi-disciplinary patient assessment, education, surgery details, skilfully performed implant operation, post-operative follow-ups, early and ongoing support for the implant recipient will work better.
Support for change	I think this will be a positive move, everything will be easily accessible and all at one place.
Support for change	Centralising a service which serves a small number of the population allows resources to be pooled and staff to gain more experience. This also gives a fairer service and safer.
Support for change	This would be a brilliant idea.

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Support for	Having the facilities for adults and children under one
change	roof would make more financial sense.
Support for	I agree with what is proposed.
change	Descripting that a wider range of enecialist skills would
Support for change	Reassuring that a wider range of specialist skills would be available.
Support for	It would be more beneficial to the MDT to be able to
change	maintain their skills/experience and share knowledge by
change	coming together in one location.
	denning to get in an analogation.
Support for	A main (one Hub) is the way forward for a seamless
change	approach and understanding.
Support for	Having experience of having had my preoperative
change	assessment many years ago i.e. 1996 for a cochlear
	implant at the old Bridgend Hospital followed by being
	the 1st to have the implant at the then new in 1997
	Princess of Wales Hospital. I agree wholeheartedly with there being one centre with the required service listed.
Support for	Feel the expertise would be in one place which should
change	be a good thing.
Support for	All under one roof would be better and to see
change	consultants quicker would be great (I have no problem
	with the Royal Gwent Hospital).
Support for	It makes sense to provide one central hub for patients
change	and staff.
Support for	Hope it would give more people with hearing problems
change	access to either implants, As Doctors, Nurses and
	hearing .specialist available to help.
Support for	Needs to be robust centralised service, not piecemeal.
change	
Support for	My understanding is that it has been practiced and tried
change	with a positive outcome. That will benefit patients and
Company for	staff with hopefully the best outcome.
Support for	I believe a single unit designed to treat all BCHI patients
change	would enable all patients and staff to concentrate on this specialist area of medical treatment.
Support for	If it means that more operations can be carried out then
change	yes it's definitely needed.
Support for	It would be great for Adults and children to have one
change	unit
Support for	I agree with this option because both Cochlear and
change	BCHI, Bone Conduction Hearing Aids, would all be under
	one umbrella. With the right staff who understand how
	people with profound hearing loss feel, cope and deal
	with every day with this very real disability.
Support for	I feel centralised services would be more joined up and
change	accountable

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Support for change	It is good. It is better to be in one place so people know where to go. Staff will be with a specialised team. If it is in one place, it may be difficult for some people to get to. One member said she doesn't use hearing aids so she doesn't know much about them. It is a good idea to have a single implant centre. Good thing for children and adults to use the same centre. Keep the same staff as it is good to have the same nurses.
Support for change	I agree, more service users would benefit
Support for change	I have no comment about the preferred option and I agree with the preferred option as a positive option.
Support for change	All the required skill set in one place.
Support for change	Easier for everyone to liaise & patients.
Support for change	It is the only option to achieve the aims stated.
Support for change	Centralised services for Cochlear and Bone Conduction Implants will get together highly specialised equipment, resources and specialist expertise in one place. This is a recognised model of delivery highly specialised services to relatively small number of patients, but all of the recipients have got a new lease of life! I would like to benefit from more timely resolution of problems - technical and clinical. A centralised service will have better connections with the industry and more timely upgrades of process and novelties. It is necessary to have accurate information as to who and how to call with any problems and the response service to have a patient advisor present.
Support for change	better to have a central team at one location
Support for change	I think it will make more sense than in the previous options, it will be able to budget and also allow/include the much needed help that will be offered with this new option.
Support for change	I agree and understand why services need to be centralised, for financial reasons and also the usage of services by the clients. I visit Cardiff University Hospital
Service design	and have been for over 25 years even though I live in Carmarthenshire. I do have a worry of integrating children and adults in the one hub/department unless appointments are staggered.
Support for change	In an ideal world with money no-object a number of centres is the answer. I can understand that for some people travelling further can be difficult but to access

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Travel and costs	this excellent service we should be prepared to pay additionally towards it. Maybe there could be some funding provided for travelling for patients who would struggle to meet the costs.
Support for change	I agree one place does everything for deaf people.
Support for change	The most important thing is the experience of the person setting up the hearing aid to give maximum benefit. If you have to travel for this it is worth it.
Support for change	As long as it provides a first class service to all - and completes necessary operations in expected time scales.
Support for change	A single hub would streamline the problems faced by all patients with various/different levels of hearing loss. All patients and staff would only be focussing on deafness leading to a superior service than is currently available.
Support for change	Accountable, joined up, patient focussed.
Support for change	I think it's a good idea to have all the right staff and experience in one location instead of being spread between several sites. This would benefit peoples aftercare and when the patient needs advice on any problems that may occur. Cost of one location would be easier and reduce travel costs for staff between sites.
Support for change	A single center at Cardiff would suit me as I live close by.
Support for change	I think all the proposals and actions are ok.
Support for change	It would be a good idea to the BCHI and Cochlear Implant Services in one hospital, but I can drive!
Support for change	I believe this would make the service more of a nucleus for the S Wales area and consolidate the skills of hearing/audiologists/D/deaf specialists across this part of NHS Wales. By bringing staff and expertise together, better care can be practiced. A trained and responsive Outreach service at local audiologist deaf units would enhance the hub. This is very important especially as someone who was referred by an audiologist with strong knowledge of Cochlear Implants.
Support for change	I do think this is a great idea especially if it helps people get the quality care they need and a shorter waiting time will be helpful for many patients.
Support for change	Having one team of skilled experienced specialists in one hub can be a huge benefit to implant surgery. It is however vital that regional outreach support is maintained as access from across Wales to one central hub is not practical for all.

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Support for	I think it will make referrals easier and give a more
change	equitable service
Support for	It is better to have all staff in one place instead of
change	having to bounce around hospitals. However it must be
	central and easily accessible.
Support for	I think that by having a single hub you will have access
change	to specialist surgeons and better facilities to better help
	patients.
Support for	1. Would provide a service with an equitable level of
Change	quality and standards across Wales. 2. Would have the
	same level of governance and accountability. 3.
However	Sustainable - if the financial appraisal has shown Option
concerns re	D to be most cost effective. 4. Opportunities for service
increased	development along with technological development.
travel times	Negative: Socio-economic issues with increased travel
	times and potential lack of local engagement to CI and
	BCHI users who may be negatively impacted by loss of
	local hubs.
Support for	'High volume surgical sites' are key for good outcomes.
change	At the same time follow up services should be 'local to a
	patient' for better compliance & outcomes
Support for	Because waiting times would hopefully improve and
change	staff shortages decrease
Support for	Preferred Option: A single device hub ensures and
change	maintains professional input & status, and the outreach
	support enables access for all service users. It prevents
	a watering down of the service.
Support for	I agree because there are specialists who know their
change	job. So I believe they will make the right decision on a
	preferred option.
Support for	No matter where in Wales the hub is. The travel is a
change	small price for me personally to pay to receive my care.
Support for	I consider the change in service to be prudent and the
change	only sensible option
Support for	Financially better to have adults and children together
change	to keep the service going. Better qualified staff with the
	skills that are needed, and more implants can be offered
	to people who need them.
Support for	It will leave more travelling for many patients but,
change	ultimately, give a more specialist service and save NHS
onange	costs, which can be applied to provision of an even
	better service.
Support for	The quality of the service will be enhanced. Providing
change	outpatient assessments at outreach sites will minimise
- Change	the impact of inconvenience of travel.
Support for	It will be better than before. I am more interested in the
change	Cochlear Implant System than the other old hearing aid.
Change	Cocinical Implant System than the other old hearing alu.

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Support for change	Hopefully more people would have access to the service or be referred to the service at the appropriate time (I wish I had been referred 30 years earlier). Hopefully the preferred option would provide more awareness medically and within the community, therefore obtaining professional status.
Support for	Minimal impact for me. Improved
change	specialism/consistency of service.
Support for change	Job well done.
Support for change	Minor inconvenience for some people, but fairly small number of people affected and most will just be grateful of the opportunity to have cochlear, etc.
Support for change	1. Hopefully the service will be better as the surgeons will do more procedures and hence gain more experience. The associated equipment should also be
	better. 2. In general patients will have to travel further. Nothing much you can do about that although maybe some consultations could be done remotely, although clearly not hearing tests. Maybe some assistance with travel could be provided.
Support for change	I think it will impact patients in a beneficial way in most senses, however I believe they will want all their care closer to home.
Support for change	I think it would have positive outcomes
Support for change	Quicker response, better service, skilled staff. I received my implant 12 years ago. Everything went smoothly and I am very grateful to all the staff involved.
Service design	However, after my operation, I was put on a general ward, which was very difficult for the staff and myself.
Support for change	Sincerely hoping that you will be able to maintain and offer the high levels of access, communication and care I currently receive at UHW/Cardiff. Benefits of relocation may be easier access, ie parking or access by Public Transport, though doubt that's achievable or realistic for many of your patients. Hoping you keep your current highly trained staff.
Support for change Location	So much better for patients to be in one place, we all have different needs, therefore if all specialists are in one place, it would be so much easier all round. It's just a shame Mid Wales is forgotten and it takes 3 hours to get to my hospital appointments one way.
Support for change	More centralised services would mean that specialist teams would have a better opportunity to maintain their skills and would mean that finances don't have to be

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	split across a number of services; therefore would be more beneficial from a financial perspective.
Support for	I feel the service would become more robust ensuring
change	the correct staff are seeing patients
Support for	Better continuity of care provided. I do worry about
change	access as living in Swansea and coming to Cardiff has
	sometimes proved difficult especially on surgery day as
Location	we had to find a hotel, etc. The whole Team were
	nothing short of amazing and the care I received was
Service	second to none. By pulling all the services together, it
feedback	can only improve.
Support for	I think it will make more sense than the previous
change	options. It will be able to keep to budget and also allow
change	included the much needed help that will be offered with
	this new option.
Support for	Faster turnover of patients' appointments, less frequent
change	technical issues during clinical appointments. The
change	personnel is likely to be more involved in patient's care
	and outcomes in comparison to the service "borrowing"
	personnel from outpatients' departments of general
	hospital. I believe such service will be able to arrange
	timely and expertly dealing with emergencies. It can be
	, , , , , , , , , , , , , , , , , , , ,
	the hub for training health professionals. It can develop
	research unit. It can facilitate patients' support groups,
	further education and training in using the implants for
	improved quality of life of the recipients. A Centralised
	Unit will measure up very favourably with other UK and
	International Units. I have benefitted tremendously
	from the skills and professional expertise of UHW
	Cochlear Implant Service. I cannot praise them highly
	enough for the years of support I have received. I
	believe that the Cochlear and Bone Conduction Implant
	Services in Wales have got a bright future and should
Commont for	be supported throughout
Support for	More difficult for those living at some distance. But a
change	'Centre of Excellence' is certainly a preferred way
	forward. Outreach support must be fully supported and
	not just pay lip service to the idea. Staff must be fully
	trained and supervised to a high standard wherever
	they are based.
Support for	probably a better service, although the current
change	arrangements are excellent
Support for	It would be a lot better as you are able to see the same
change	people (surgeons and audiologists) whenever you have
	an appointment, so that you can build up a
	patient/Doctor relationship that most people like myself
	miss.

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Support for change	Centralisation = Centre of Excellence. Retain qualified staff, maintain Dr numbers and allow cover therein. Possibility for innovation. Transport arrangements would prove difficult for more people.
Support for change	It would be very worthwhile building a specialised hospital where it would enable a high end patient care ad understanding. All Doctors and their Team in a central place would benefit everyone, creating more jobs, more specialised care.
Support for change	You can never please everyone, but this appears to be the most sustainable option.
Support for change	A far more accessible and specialised service for both the health providers and the patients
Support for change	I'm sure it should be a big improvement, mostly to relay any problem that us current users face. It can only be a good thing if children/adults who need help with the hearing problems are sorted quickly. I'm lucky enough to have had a BCHI (BAHA) at Singleton almost 30 years ago. Wish it was available when I was a child/teen. So pleased for children today [to be able to receive this Aid].
Support for change	Better service access, knowledge imparted and improved links with local services, especially audiology teams, (if outreach audiology appointments), a possible increase in the number of people being referred/considering implants, consistent approach
Support for change	1. Would have more in-depth skills in one centre. 2. Would provide more consistent appointment fixtures as there would be more specialists on hand to cover
Location	unexpected absences. 3. Unfortunately, would mean significant number of people might have a significant increase in travelling time and therefore additional cost, as well as travel stress.
Support for change	Better all round. Makes sense to keep both sections in one main centre with Outreach Support.
Support for change	Improved individualised care.
Support for change	I agree mainly because I think it is very important to employ and keep the highly qualified staff necessary for the service to be provided.
Support for change	Yes for clinical reasons it makes sense but not sure if patients would agree
Support for change Location	The impact on some would include, increased travelling cost and time. But having said that as a BAHA wearer, the positive impact of having this aid, far outweighs any negatives of slight upheaval of having to travel a little further or taking a day of work instead of say half a day.

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Support for change	Waiting lists would be reduced. GP's would know exactly where a patient would need to be referred. Staff would not be called away to cover other areas - this does happen in multi disciplinary hospitals/clinics. Improved communication between patients and staff. Allow for longer consultations. Better understanding of complications following cochlear implants. Patients would know exactly where and who to contact should problems arise. Overall a single centre to deal with BCHI simplified referral, consultation, surgery and all future necessary follow-ups which are essential. Adequate parking.
Support for change	Improved individual patient care.
Support for change	I support Option D. If that is the preferred option I think the impact would be best. An outreach support model would then be available for everyone, whenever necessary.
Support for change	To enhance the lives of people with profound hearing loss. More public awareness by being a centralised approach for Wales. A hub for excellence.
Support for change	A one stop 'SHOP' - all in one place. Great!
Support for change	There needs to be more help and understanding of the deaf community and maybe a complete unit dedicated to this would be an asset
Support for change Workforce balance	Firstly I wouldn't want there to be an impact on the workforce's work/life balance by having to change work place by excessive commuting, etc. This needs to be managed sensibly. Having previously been a patient at West of England Cochlear Implant Programme, I felt at ease and safe in their care. Larger travelling distances for patients might be an issue, but with good care, long travel shouldn't be consistently necessary post-implant. Good workforce/patient relationships should be maintained if a single hub is the option. Some patients may be too used to the current set-up.
Support for change	A better and quicker service while some of us have to travel further. I think it will be better for us in the long term, with all the right staff and facilities in the right place.
Support for change	All things considered, it would benefit everyone who needs assisted hearing aids which are essential, as I for one am very grateful for mine. I think if it makes the process easier I'm all for it.
Support for change	Benefit for all - staff and patients alike. Increase in referrals. Especially important for children as early

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	diagnosis and help is vital. Having been profoundly deaf I consider my Cochlear Implant to be a "Miracle". Any improvement in the future provision of Cochlear and BCHI is to be welcomed. PS: Many thanks to the Cochlear Team at the Heath Hospital!
Support for change	On the basis that the central service provides enhanced care then this can only be a positive step.
Support for change Travel	I think it will result in some patients have if to travel further , but they would be seeing a more experienced team
Support for change	A positive development for the CI service, formalising the current arrangement and enabling the service to move forward. A centralised MDT could be helpful for BCHI, making things more co-ordinated and potentially leading to more people receiving BCHI. However, it could also be detrimental to patients if care is unnecessarily moved away from their local area.
Support for change	A better, more integrated service for children and adults.
Support for change	An improved service and a higher skilled workforce
Support for change but concern on travel cost	The only disadvantage is the additional travelling expense where patients reside far from the hub.
Support for change – though no location determined as yet	As stated above and cost effective service will maximise professionalism. A "Centre of Excellence" in Cardiff.
Support for change – though no location determined as yet	My BAHA was fitted in Birmingham so I have no experience of the implant service in this region. A single hub for the surgery and implants seems a sensible idea. If the ongoing support remains in the same place as now, then there will be no change for where I access my audiologist. Having most appointments closer to home is better for most people.
Support for change – though no location determined as yet	I agree with the option if this means more patients can be seen. Would it mean an enlargement of unit at the Heath to accommodate extra staff/patients? Hopefully more cost effective. Would there be more outreach units?
Support for change & location	I agree that it would be beneficial if there was a centre of excellence. My concern would be location as the area

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	covered in these proposals would mean travelling when transport is not the most reliable without a car.
Support for change & resources	I agree if there is a single center they will provide a high quality service but in my experience they need to have regular dates and appointments. My sons appointments were cancelled several times and one of the reasons was because they were short staffed in a "big hospital"
Support for change & Resources	Suitably trained staff and facilities at one location.
Support for change and general patient position	I have the Cochlear Implant and I became independent since they gave me the implant. I used to be dependent on other people. I know it would be better for every patient to get better services and support for South East and South West Wales and South Powys. I also agree that a single centre would be better and able to provide a high quality service too. At present the hospital service is not able to provide good quality service due to the NHS funding cuts.
Support for change and location	If it means more staff and more people having the op. Yes I'm all for it they are just wonderful at the UHW Cardiff but transport getting to the hospital not everyone has a car but having one place makes sense.
Support for change but concerns on location	I agree that specialist services would be better served where more staff can be accommodated in one or two centres but, as explained above, hope that this is in my areas.
Support for change	If everything was in a central place then standards would improve and the service provided to patients would be better.
Support for change – access	Access may be an issue as some patients and their families will have to travel further but to get excellent standards of care the service needs to be centralised
Support for change – general patient position	I would like to agree because the problem I had before my op. was that I had to wear 2 aids in my ears, the hearing aids caused a lot of infection and irritation, had to go to the hospital every week to have treatment. When I had the chance to have the op., it was great. No more infections and irritations, and a better quality of hearing.
Support for Cochlear centralised but not for BCHI	Whilst Cochlear Implants can benefit from one centre I'm not convinced just having one BCHI Centre is beneficial.
Support for proposal	Yes, the service offered needs to be cost effective (to obtain ongoing funding). Accessible through all stages of

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	delivery and safe. A good robust service not a smattering.
Support for service	I personally can't fault the care and service I have received
Support for service and service feedback	It makes sense to rationalise the service and retention of specialists. Post-implementation I would still like to see more D/deaf specialist mental health provision including counselling.
Support for single team	The access to timely surgery would be a great outcome here. We also struggle as a small team to dedicate all the admin time to provide figures for the BCIG meetings, if this is managed by one team this would be great.

#### **NON SUPPORT FOR CHANGE**

More services needed	It would be a good thing if Cochlear were done in more hospitals.
No support for change	Centralisation doesn't work. Staff are wonderful but getting to you is not good and there's many much further away than us. If you need to save cash get rid of Managers, etc. and get more nurses and doctors.
No support for change	I could not agree with a proposal for one centre given the difficulties for many of your customers to travel. It is already too far for me to travel to Cardiff as it is.
No to centralisation	The arguments are not convincing. There are movements in Wales into having things done centrally. Generally, patients like things done closer to home. The NHS is under pressure at all points. It has coped well, everywhere, with covid
Option suggestion	I think it's better to have Option B.
Option suggestion	I think the impact would be to go for Option B.
Single centre challenging	Having a single centre for CI/BAHA is challenging, surely, for staff intervention. It's a huge catchment area, meaning travel eats into staff hours (for QTOD visiting children).

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#### ACCESS, TRAVEL, LOCATION, PARKING & COSTS

Access	Accessibility for patients
Access	It has to be accessible to all ages, socioeconomic
Access	groups.
Access and	Accessibility is the key problem for me, already having
location	issues with train strikes, limited timetables for all
location	public transport.
Cost	Please assure people on their own can access
Cost	appointments in a timely and not costly manner. I
	have to go to Bristol Eye Hospital - no appointments
	after 3.00 pm - or transport won't accept. The single
	from Bristol home is about £200! Not on a pension it
	isn't - I won't/can't afford it!
Costs	Patients could be asked if they can make a donation
COSCS	towards costs. Whenever greater expenditure would
	create greater savings this should be looked at.
Location	Personal concerns that the issues may affect my own
Location	access for any issues, concerns and follow-ups in the
Positive team	future. I have thus far since March 2021 had
feedback	exemplary care, communication and access to the CI
- Codback	Team at UHW.
Location	No issues as such but I do think Bridgend Hospital
20000000	should still be seeing patients that had their operation
	there with Mr Backhouse. A wonderful service and
	Cardiff is too far to travel to.
Location	More of a local service - no further than Cardiff.
Location	The only objection I would make is the location of this
	unit, you have stated that you are using Cardiff as a
	temporary base but that is where you intend it to be. I
	will object to this location and I think it should be
	moved back the Bridgend, it is extremely difficult to
	travel from any part of West and Mid Wales to Cardiff
	by road or rail, parking is impossible, taxi fare from
	the station is £15 to £20, Bridgend is more central to
	all.
Location	I cannot fault the service but it's a shame that I have
	to travel to Cardiff to be seen as they closed POW.
Location	Travelling from West Wales to Cardiff is just too far.
	My family travelled miles to Bridgend but Cardiff is
	ridiculous. Why if there is to be one centre does it have
	to be in Cardiff? Why can't it be more central?
Location	Residents from West Wales to Cardiff would have to
	make a long and often tiring journey. Bridgend is quite
	far already, but travelling further to Cardiff would take
	an entire day. A service that is located in a more
	central region of Wales would be ideal and accessible.

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Location	Understandably, patients want local access to services and are reluctant to travel far for those services. Similarly, the health boards also want local services but the specialist nature of the service limits the extent to which each health board can keep the service within its own boundaries.
Location	If I may be so bold as to give my personal view on the location of a central Hospital, then The Princess of Wales Hospital in Bridgend would be my choice. Clients living in Pembrokeshire or even the rural areas of Carmarthenshire find it quite stressful driving so far east to Cardiff.
Location	I do not think the needs of the patients have been prioritised, i.e. the need to go to a near, accessible quiet hospital.
Location	This sounds fantastic to have this facility all under one roof. I don't disagree but please consider people who live in rural areas and the valleys where I live, as transport isn't easily available especially if you don't drive. At the moment I go to the Royal Gwent which is easy for me and I could get a bus there. But Cardiff and further afield would be a problem especially if you can't drive (I do drive) so please consider this when deciding where you're going to place it.
Location	I am not clear how the proposed change will affect me. The change to the service seems aimed at those people yet to receive an implant. So it would be better to ask them - except you can't as you don't know who they are. For myself as a patient with an existing BCHI (BAHA) I have periodic reviews and check. These currently take place in the Royal Gwent. Will this still be the case or will I need to travel further to the new central centre?
Location	I agree however, I think the location in which you choose to put the centre is very important, as it needs to be accessible to all patients.
Location	I hope this option will improve the quality of care and I also hope that I can attend a specialist closer to my home.
Location	It would have to be in the Swansea/Bridgend area as Cardiff is too far East and with older patients and less public transport, the appointment would take a full day.
Location	My only question is WHERE? There was nothing in the report to suggest where the new care centre will be
Location	Cochlear Implant Clinic needs to be more Central Cardiff - is too far East for most people.

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Location	Although the preferred option appears to be the most suitable, until I know where the Main Hub will be situated, it is difficult to pass a comment.
Location	Although I do agree with the preferred option and its supporting arguments, I do find it disappointing that as it is all centred in one place then it will obviously have a significant impact on travelling time for many people.
Location	Neath Port Talbot ENT has been and still is a very good clinic, and I hope it will continue to be the clinic that I can attend.
Location	If there were enough referrals and enough staff, Bridgend would be my choice to continue to have the 2 hospitals giving a service to hard of hearing children and Adults.
Location	It would all depend on where the centre is based. At present some of my patients refuse to travel from NHH to RGH so if it's based in the Heath or Bridgend I think a lot of my patients may decline BAHA.
Location	Where do you propose to locate the single hub?
Location	As long as it is not in Cardiff a lot of users would benefit, people including myself would be put off with hassle day trips to Cardiff
Location	People living in far reaches of the area that provides hearing devices have a hard time reaching one hub, especially in inclement weather
Location	I would need details on the location of the single hub before I could answer. Cardiff would be my preference.
Location	At present I'm seen in Neath Port Talbot Hospital and this is very difficult for me to get to. I would very much prefer to be seen in Singleton Hospital as I did a few years ago as I can get there much easier. I live in Pontarddulais Swansea and if there is a centre for hearing loss closer to my home and on a bus route, that would be much easier for me.
Location	Staff moving to central hub and patients' concerns regarding appointments. Difficult to travel to. I myself had a very good experience with very helpful and professional staff when I had my Cochlear Implant.
Location	I find it hard enough to travel to your centres as they are - one centre would be too much.
Location	I had a cochlear implant at the Heath Hospital in Cardiff (deferred from Bridgend). As I live in South Pembrokeshire it was a long way to travel. However, the benefit of having the Implant far outweighs problems of distance. Help towards travel expenses is available from the NHS if needed.

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Location	I currently have BAHA 6 Power. Struggling to get settings correct which can be common from comments on Facebook Group. Would be difficult and I imagine patients would persevere less if they had longer to travel. Would you still be able to have settings adjusted locally? This would be important to me. Do you offer the Osia 2?
Location	Think it would impact patients as there have been too many changes already. People want to be seen where they have been seen in the past!
Location	Distance from hub and travel time for patients will be concerning and could be problematic. May result in an increase of patients not attending.
Location	Too large, anonymous, patients are not familiar with staff and feel insecure and apprehensive. Harder for relatives to visit.
Location Service feedback	This would depend on the strength of the outreach support model. Visiting Cardiff from West Wales is a big undertaking - can you imagine doing this with a newly implanted Aid on public transport? If the outreach centre was located in an appropriate location then it may be considered more desirable. Also if you have transport the parking at Cardiff is horrendous. I think that people would miss appointments and feel dread at the thought of going to a big impersonal centre. At Bridgend we were known to staff and made to feel welcome and the service was second to none. The hospital was easy to get to with adequate parking. At the moment with one centre it feels impersonal and rushed. The staff seem rushed and there is little time for the care I feel should be provided for such an important part of my life. I think the impact would be very negative and with the number of adults and children with implants increasing it seems illogical to decrease the service - which I feel is already not as good as it was.
Location & resources	The following problems could arise for many people: 1. Distance they will have to travel; 2. If no car available; 3. What will be the bus service to the location. West Wales patients may have a tremendous distance to travel if the hub is situated in Cardiff for example. The principle in respect of expertise and staff levels is good. But at what price to patients? At present, Swansea, Cardiff and Newport Hubs means patients travelling. Could be more suitable and less distances involved.

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Location & travel	If possible could we have Baha Bone Anchored Hearing Aid facilities in the Ceredigion area as travelling on a bus to Neath or Cardiff hospital would be too much for a pensioner even myself when during COVID I had to pop into A&E as I developed an infection and not one person seen one of these so thankfully I had a work colleague with me and between us was able to explain what is required but it was a struggle
Location and accommodation support	Having to travel to a central hub may put some people off having the surgery which would be a great loss to patients of the absolutely massive benefits of an implant (it changed my life for the better by an enormous amount). So the correct support may be required even providing accommodation for the accompanying relative if needed. For the surgical procedure, an overnight stay in hospital.
Location and parking	I am very sorry that the unit at Bridgend is closed. As a person who has been deaf for many years my confidence levels was very low and I become reluctant to attend medical appointments. However, the small group was friendly and warm I was immediately put at ease and was happy and relaxed throughout the procedure and actually looked forward to the visits. The hospital was easy to get to and parking was not a problem. I have found the opposite to be true of Cardiff, it is extremely busy hospital where you have to wait to be seen for a long time. It's impossible to park and have to drive out of the hospital grounds and park on the roads outside. I am confined to a wheelchair and makes life very difficult.
Location and parking	I somewhat agree but there are areas to be considered such as the location of the model. As mentioned previously, the location should be more central, such as Carmarthenshire, thus meaning more people have access to facilities. Parking would need to be of a decent quality. Cardiff has poor parking. In addition, public transport would need to be considered, as not all people with cochlear implants or have an implanted child are able to drive. One singular centre would possibly fail to provide efficient facilities and support and time - especially to newly implanted people and their families. I believe going ahead would be a mistake due to the extensive journey which in my experience is very tiring, as well as the tuning sessions being exhausting - adding hours of travel into the mix amplifies my sheer exhaustion. In addition the system feels very rushed, like patients are tasks to complete

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	instead of people. Growing up, Bridgend was personal to me. I recall being greeted, updating staff on my life and felt more than a list. Taking the next step could discourage people from choosing to be implanted as they will have to take constant tests at the hospital in the immediate aftermath of the surgery and the activation of the implant. Prior to taking the next step, I strongly believe consultation with patients and their families would be ideal as relying solely on data and financial costs would be a severe mistake.
Location and Resources	Fewer staff & facilities offering higher level of service to patients. Patients having to travel further for treatment etc.
Location and service design	It is biased. While less strain on services, some people find it difficult to travel and a single hub may result in people not getting the help they need. You would not have one optician for the whole country, why should ears be different?
Location and service feedback	I had my CI in March 2021 during the pandemic at UHW. From the first consultation I was received by a great team of highly trained and professionals individuals who helped me make my decision into accepting CI which was done 3 months after my evaluation and clinical decision making appointments. UHW is easily accessible for me although I live 34 miles away, parking is a nightmare. i have had amazing support from all of the CI team at Cardiff and hope that will continue in the future, wherever you decide to base the unit.
Location and service model	Sustainable hubs for outreach support model for patients needed. Many will be concerned regarding access to local facilities.
Location and travel	If this facility is too far away, how are people going to get there?
Location and travel	I have access to UHW which is convenient for me but many others will have travel difficulties.
Location and travel	My only problem is getting to the University of Wales due to a walking problem so I have to ask the Ambulance Service for help; they have always obliged.
Location and travel	Currently I attend the BCHI Unit within the ENT Clinic at Cardiff University Hospital. I live near Pontypool and would NOT wish to travel further than I have to in the future.
Location and travel	I agree with the aims above, but would still prefer to have the services at Bridgend to reduce the need for travelling a long distance for children and the elderly.

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Location and travel	Although the desired level of service should be assured, the main impact will be on patients who have increased distance to travel for appointments and surgery. For some this may discourage them from attending.
Location travel and cost	My concern will be accessibility for patients who will have further to travel. Will the additional travel costs be funded? I agree with idea of all services under one roof but will this lead to staff being made redundant?
Location, transport and cost	Although I understand the preferred option, I am concerned about the location and travelling further for treatment. I already travel to London for treatment that cannot be met in wales. I am struggling financially because of this, as I am not entitled to travel expenses. However, you dress this up it is a down scaling of services. I had to go to Cardiff for brain surgery as the centre at Morriston hospital was closed. I have also had to attend Cardiff for other services because they cannot be provided locally and the waiting times are longer than local and not acceptable.
Location, transport and training	1/ Cause distress and expense for patients who will be required to travel further for all appointments. 2/ Patients referral to be assessed for an implant at a centre living further away may be impacted. 3/ Will training skills for all staff in all areas be maintained at present levels. 4/ Will aftercare following implant and switch-on be affected.
Location, travel and cost	Yes very much so. Taking away Bridgend causes so many travel problems: 1. a train & then 2. A bus. Parking at Cardiff Hospital is ridiculous and not up to standard for such a large hospital. As I am a pensioner, this means paying high train fares.
Location, waiting times, service feedback	I understand the issues the services are facing. I do agree that it should be moved into one location. My main worry is that the wait time to have the appointments and surgeries may be longer. As stated before in the survey, it already took 8 weeks for a adult to be seen for a referral? This fact is based on the hospital in Cardiff, the highest population in Wales. This could take much longer now as more patients are going to one location. Although the Activity rate should now be increased which would be the positive.
Location/Access	I have been a user of cochlear implants for the last 27 years. I would agree I have had regular appointments with consultants, surgeons and audiology. My only concern going forward is for follow up procedures when things go wrong as a user we heavily rely on them and

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	without them we simply loose confidence, cant join in, have difficulty at work and can be stressful.
Parking	Easier parking than the Heath Hospital. More help needed to those living along to use new devices, etc. Particularly the older element.
Transport	Centralisation - no mention of transportation arrangements.
Transport and cost	Only concern is transportation for non-drivers, low income/elderly
Transport and cost	I agree that after service of the BAHA in local hospitals or local surgeries are a good thing for transport costs and convenient for patients.
Travel	Some patients will be less likely to opt for BAHA due to travel commitments. I struggle with a small minority of CI candidates who do not want to travel to Cardiff for an assessment. It provides a barrier to some. Otherwise, it is a good idea.
Travel	I am concerned about the apparent travelling difficulties created by the proposal.
Travel	One Hub will make travel harder for patients.
Travel	Whichever the option, some patients are going to travel further.
Travel & service improvement	Easier access, locally provision of service, less travel to the centre which can be difficult for some patients, may encourage improved joint working and knowledge of the implants amongst local health board services
Travel and cost	Potential for a more complete service. Longer and more expensive travel for some people. Will staff have to relocate?
Travel and cost	Would travel arrangements/costs for out of area be available?
Travel and location	Understand the need of people having to travel to centers. Make it easier for rural patients and for those who find access to one center difficult. It could be done.
Travel and location	There will be an impact for both staff and families, particularly for areas further afield. Putting all your eggs into one basket as it were?
Travel and location	If the hospital is long way for some patients to get there without a car it could be a big deal for them. I live in the valleys and buses from our village only run every 2 hours and stop at certain times, so for someone without a car would be a big deal unless a transport service was made available for them.

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Travel and parking	People might have trouble getting to the hospitals and parking is always a nightmare. Help to set up appointments would be helpful.
Travel and parking	Congestion in the Heath Hospital making waiting and travelling a problem. Parking in Cardiff is always a problem. Allowing time for catching buses for people
Resources	from far away could cause stress. Staff shortages causing congestion of patients waiting for attention. Too many operations for the surgeons to perform. Too many people waiting to be seen.
Travel and waiting times	Travelling difficulties and a possible greater inflexibility in the availability of appointments.
Travel, Service design Process	A poorer service. Increased costs for families living in West Wales. Increased travelling times. Whilst this is couched as a 'consultation', I believe the decision has already been taken.
Travel, resources	Personally little impact. Potential however, for other service users to feel that there may be: 1.a lack of local support; 2. financial detriment to attend appointments. 3. Feeling of inequality due to location. 4. It would end in essence 'postcode' lottery - not in terms of treatment or expertise but would ensure consistency. 5. There would be a decrease in staff pool for the services provided. This would mean potential staffing issues should you have retirement/relocation of staff. It would become an extremely specialised service. It will unfortunately mean some staff would also become de-skilled.
Travel, waiting times and staff development	Impact will be longer travelling, local services will become less patient specific. Waiting times would increase due to everyone treated in one place. Less opportunity for consultants and other medical staff to progress locally and opportunities only available in large centres.

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#### **STAFF & RESOURCES**

Resource	Financial was a main consideration.
Resource	Whilst I agree that a single centre is best, I would want to see NO reduction in staffing resource by centralising. We have seen that centralising other services has worsened service. If the same full time equivalent resource is centralised then it may work. Ideally, I want more time available for CI mapping and enquiries.
Resource	The effectiveness and efficiency delivery of the preferred option is dependent upon the availability of specialist staff
Resources	The shortage of fully trained staff and the one hospital closed is awful. We need more staff and more money to enable this much-needed work to be achieved.
Resources	The Government needs to fund services better.
Resources	Enough staff is essential.
Resources	See above. I am aware that the NHS is under huge pressures. Having one hospital, as a centre for surgery will surely put compromise on availability of beds.
Resources	For all of the above to be achieved I think will take a long time. It needs much more funding.
Resources	the success of delivering the future aims is very much dependable upon consistent funding
Resources	Finance prevents more than two hubs
Resources	You mention a central hub. Where would this be based and at what cost to the Sennydd? Would this be part private funding? Will existing staff be prepared to move to provide same service? If not, what skill base can be retained? In the current climate within the health service, how far down the list for this vital service do you see yourselves?
Resources	Preferred Option: I would hope that it will be sustainable to fund the change of staff to implement this preferred option.
Resources	I worry it will be an excuse to cut overall staffing - if this happens, no progress will be made. I am now in year 2 since my CI. I believe not enough time is given to mapping - as a result, my confidence has eroded as my CI experience has declined through mapping being done in a rush.
Resources	Staffing shortage with Princess of Wales Hospital Cwm Taf Morgannwg being closed
Resources and training	Enough patients seen to ensure staff skills are adequate

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Resources travel and cost	Alongside the changes proposed we suggest some families will face additional time and financial costs associated with travel into Cardiff. Whilst some may be entitled to a travel reimbursement, they will still be required to fund the up-front costs associated with the journey. Additionally, for some families, the appointments will require a full day away from school / work and this may negatively affect patient experience. Any unforeseen problems arising from surgery will not be dealt with locally; therefore, some families may be required to commit to additional journeys to receive the right care and support. Investment to support communication from the host site to local services will likely be required to ensure local service systems can be automatically updated. Families' emotional needs should be considered in these proposals and responded to as appropriate.
Staff	Good if it works. Lot of work ahead though. Continuity of staff. To us they are friends.
Staff, training and funding	long term, consistent funding is a concern, especially for training, retaining and replacing specialist staff within a multidisciplinary cochlear/audiological team
Staffing	I can see the problems with staffing. Would the staff from the other hospital be employed by the Heath Hospital?

#### **SERVICE DESIGN**

Service design	Make a weekly hub
Service design	The issue for those with BCHI/BAHA is how the
	arrangements for dealing with regular infection flare-ups
	is CLEARLY stated to BAHA patients, and early entry to deal with infections is paramount!
Service design	Local outreach and access, including audiology
	appointments and rehabilitation appointments would
	enable ease of access
Service design	Is there any plan to make more use of digital support
	for follow up care? I have managed very well with my
	implants using headsets and Bluetooth. More training
	will be required for both patients and staff on this.
Service design	Many people did not come forward during the pandemic
	to get advice about their hearing. The number could
	increase as time goes by, needing more operations.
Service design	Have to consider number of CI and BC patients which
	are very small considering population of Wales.
Service design	As the number of patients using the CI and BCHI service
	is relatively small it is reasonable to centralise the

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	Inpatient aspect of the service. However, there are many of the Outpatient aspects that should be provided at a more local site to reduce the impact of travel particularly for patients living in rural areas of West and Mid Wales. For example, initial assessment with Hearing Tests, CT and MRI scans should be available locally. Similarly, post-op assessments could be carried out near to the patients' home.
Service design	We need more hubs; I have no problem with children & adults being together but what next? Will we be going to Bristol next to save cash?
Service design	Where will the hub be? It must be easily accessible by public transport as well as by car. Will there be dedicated parking spaces for clinic/surgery attendances? Will attendance times take travel distance into account?
Service design	The outreach support model in Neath Port Talbot will be accessible to myself.
Service design	Children need both implants in order to develop their speech.
Service design	Any future upgrades in technology and or surgical methods can be practised at this hub.
Service design	It will impact those who live furthest away, might I suggest having extra facilities available for families to stay overnight?
Service design	I agree as it gives a fairer and safer service for patients; it will no longer be a 'postcode lottery' as to how quickly and effectively a patient is seen. Largely positive, however, it could mean transport difficulties for some patients. Also, I am assuming the service would require fewer specialists going forward and whilst this may be a cost saving, it will mean there may be losses for the staff involved. Also, would current staff relocate, or would it result in staff shortages as it is a specialist area. I want to know whether the Doctors would still have a working partnership with Paediatric Plastics in Swansea Bay (Morriston) to accommodate BCHI and ear reconstruction to happen at the same time.
Service design	The centre would have to be child friendly. As a child growing up we had a special Ear, Nose and Throat hospital which catered for children so the environment was welcoming and friendly.
Service design	The impact should be better support for those with hearing loss. Support to access doctors who use BSL, access to the Deaf community, and a community of those with implants. A follow up to check on quality of life/ what benefit they have had from the implant would be easy to do. Staff could be trained to higher standards

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	if they are specialising and they would come to know the difficulties facing the patients better.
Service design	In response to increased travel, time, and financial costs for some families, it will be imperative to monitor equality of access to the specialist provision once available via a single site, adjusting policy continuously to support families access as appropriate.  • Continued investments to ensure effective communications between local systems and the host database systems should be considered.  •We expect the related services to comply with nationally developed standards. National Deaf Children's Society works with government agencies and professional groups in developing good practice guidance and quality standards that reflect the views of parents and young people.  •We suggest consideration is given to supporting the emotional needs of families opting for implant assessment, procedure, and follow-on care, which is reflected in policy, pathways and practice.
Service design	
Service design	No-one is going to argue with these aims, the argument is what services need to look like to deliver these aims.
Service design	Every children and adult (if deaf) should receive a chance of both operations i.e. whatever they need.

#### SERVICE FEEDBACK/GENERAL COMMENTARY

General	Although it may be useful to have this you would have
comment	to think about whether it would have an effect on the
	surrounding communities.
General	I don't know. I have always thought, highly, of the
comment	services.
General	I have not seen anyone for 12-18 months so cannot
comment	agree or disagree.
General	Like all new ideas, obviously, we need to find out in
comment	practice.
General	No what's the point you won't listen.
comment	
General	Easy on papers. Will it work?
comment	
General	They are used to making very difficult decisions in the
comment	NHS. I can't really comment about the process
	followed.
General	Nice that children and adults can communicate, can
comment	help.

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General	It is disappointing that this may cause any Implant
comment	Centre's to close with further hardship to staff and
	patients. I feel it is important to maintain the service in
	the best way possible for everyone involved.
General	Whilst I agree, the clear arrangements for self-referral
comment	for ear infections (BAHA) MUST be made to patients as
	they will probably be life-long clients.
General	I can only say how it changed my life to be able to hear
comment	again and to be able to speak to some people on the
	telephone.
General	From our perspective we already feel that we are part of
comment	a single hub set up.
General	Again the Heath Hospital has been absolutely amazing
comment	ever since I was 4 years old and have always been
Comment	looked after but now I have moved and would love this
	facility in the Bronglais Hospital in Aberystwyth as the
	staff there are amazing and help
General	Probably not much for me as an individual patient but
comment	difficulties for other patients. Thank you for seeking my
Comment	opinion.
General	I don't know to be honest and I don't think you do
comment	either. Only hope service doesn't suffer as this means
Comment	we suffer. Employing more nurses on better pay &
	conditions will improve the service. Less pen pushers.
	Also bring back Matrons and get rid of Managers.
General	A lot of people not getting the help they require.
comment	A lot of people flot getting the flelp they require.
General	Hope better service and regular check ups
comment	Trope better service and regular check ups
General	Essential to enable all patients to take their places in
comment	
General	society with no exclusions for persons disabilities.  Hopefully it will improve services for the clients.
comment	Hoperuny it will improve services for the chefits.
General	It would not be dire that is for certain but overall
	unsure. I was unaware that these services were in such
comment	
	a mess and would agree having these services
Concret	centralised but not affecting people is a good idea.
General	For me personally, no impact.
comment	To make it engine and make a seconditie for account.
General	To make it easier and more accessible for everyone.
comment	The insection of control of the first terms of the
General	The impact would potentially be minimal for us as
comment	currently we only attend appointments annually
	however we appreciate there could be an impact for
	others.
General	More convenience and better quality treatment.
comment	

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Cananal	and will increase
General	care will improve
comment	A guideau reconstructo to angeing people for children
General	A quicker response rate to ongoing needs for children
comment	Dy payaging to the phaya wording it averages that the
General comment	By agreeing to the above wording, it suggests that the aims can be met. I would prefer 'aims to' to be added to beginning of each of the above statements rather than 'can, has, meets, has, facilitates'.
General comment	Young persons should have priority.
General patient comment	As I have BAHA fitted I know the value. I had my BAHA fitted over 11 years ago when I lived in Barnsley. When in Barnsley I only had to attend 1 hospital for all ENT. But since moving back to Wales I've got to go to the Heath for BAHA, Llwynypia for Audiology and ear cleaning. When I first moved back I had to go to Mountain Ash for ear cleaning which meant I was attending 3 hospitals.
General Patient comment	OK but note my comments ie Welsh Ambulance times! I'm on my own, as many older people will be; transport in a taxi is beyond my means. No public transport. Even the community transport costs are beyond my means. QA Portsmouth did my surgery & was left in a ward under the care of my aunt for 5 hours! Aftercare didn't exist. Lost my Notes, refused even to remove my stitches. No follow-up. Now they tell Cardiff (excellent treatment) that I never existed! I had different hearing tests by default at QA. I could hear noise though not words properly. Now have a BAHA fitted though no ear chords - bent over.
General patient comment	By having everything in one place ensures that staff are trained to the highest standard and that patients can access everything in one place without the possibility of "falling through the cracks". Patients will know exactly where to go if they have questions or need advice. However, I do believe that follow up is important. After having my BAHA fitted last year I have had one follow up and that's it. I feel like I have been left to my own devices now. It would have been helpful to talk to other people who have an implant for support and real life advice afterwards. I do believe that patients would benefit a lot from being part of a community before and after the surgery and not just left to "get on with things"
General	It won't be good for many distance-wise. I can drive to
patient	Cardiff; I would NOT drive to Newport. If the new
position	service is as good as Cardiff - fantastic. Met a lady

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	working in Tesco - she is over the moon. Saw a little boy with an implant and showed him mine - he was thrilled. It's a good thing to mix children & adults. Let's hope many more will benefit, especially for surgery not to be in a mixed surgical environment. I heard something about teaching the children to speak with 'normal tones', including regional accents, and not sound flat. Fantastic. I just wish I could hear 'the split' and therefore learn to speak Welsh! (Being old doesn't help). Good luck. When I eventually got mine, I cried when I heard birds sing! My (name) said it was selective hearing and bad hygiene - I was 24/7 carer to my Mum. Please teach GP's. From my experience in Wales it's better - but it's so, so important. I was also refused access to a hearing dog! Thank you for my treatment this past 9-10 years.
General	I am very happy.
patient	
comment	
General	Fully aware of the difficult of Cochlear Service in South
patient .	Wales
comment	Chill a company of the safety of the said a Tanasian and
General	Still a very poor understanding of Hearing Impairment and Deafness within the community at large.
patient comment	and Deamess within the community at large.
General	The issues described are common to many aspects of
patient	life. A centralised service provides more options but
comment	inevitably makes it slightly less convenient for
	customers/clients. This is analogous to the closing of
	rural primary schools in favour of larger schools with
Conoral	more facilities.
General patient	It's hard to predict the outcome as this could be overwhelming to move into one location. I do
comment	understand that there will be more specialists at hand to
	do the surgeries/appointments and etc. The concern is
	the wait time to have these surgeries as there is now
	going to be a vast amount of people going into one
C	place. I am optimistic that this would work.
General comment	The issues described are common to many aspects of
Comment	life. A centralised service provides more options but inevitably makes it slightly less convenient for
	customers/clients. This is analogous to the closing of
	rural primary schools in favour of larger schools with
	more facilities.
General	Fully aware of the difficult of Cochlear Service in South
comment	Wales

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General comment	Still a very poor understanding of Hearing Impairment and Deafness within the community at large.
General patient position	A personal view: I am 85 next month. I was fitted with a BAHA in 2008 at Singleton Hospital. The hearing loss, in the meantime, has been considerable and it is a chronic disease. The Baha does very little for me now but I can't do without it as it does pick up a level of noise. I appreciate the good work that went into getting one of those. I attend Audiology at Carmarthen Hospital every 3 months, or did pre-covid. A local centre would be nice where the BAHA could be serviced or replaced. As far as I am concerned, it could be Option A still with as you describe on page 19: "Can be delivered through an outreach model closer to home". At my age, the closer to home things are the better. COVID has made us a lot more hesitant about going to busy places. I think the current system is good. Then, there are your groups claiming it could be improved. Despite best attention, I have lost my hearing. There were problems from a very early age. We were in London for 38 years and had regular appointments at Ilford and Whipps Cross Hospital for treatment. We moved here 20 years ago and the transition to Carmarthen and Singleton Hospitals was seamless. The hearing loss has been dramatic. It is as if the nerve endings have eroded away and there is nothing there to work on. There is an impact on our daily lives, of course. It throws a huge burden on my wife, who has to deal with all those day to day things in our lives. She jots things down for me, rather than try to communicate verbally. I wish I could pull my weight and do a share.
General patient comment	I want a good service for everyone who has hearing issues. At this moment there's not much available and it is very difficult to get help and support.
General patient comment	A more timely service with waiting times equal for all areas. Whereas now, it varies greatly between the health boards. I have been fortunate to have been treated at The Royal Gwent Hospital and had a BAHA
Support for change	fitted in 2018. I have received excellent care and any issues I am able to access the Audiologists within their department. Only this week I asked for an appointment as experiencing feedback issues. I have been referred back to my ENT Consultant as the abutment made needed to be replaced by a longer one. I have also been given an appointment for a hearing test as last one was 3 years ago. This is to see if I would benefit from the newer version of the BAHA, funding permitting. I am a

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	Nurse Manager working at (base named) and am very appreciative of the care and treatment I have received. The BAHA has transformed my hearing problems. I would be more than happy to travel to a central hub with follow ups locally.
Question comment	These are common-sense aims for any service; I can't imagine that anyone is going to disagree with this in principle!
Service needed	Essential that the service be maintained and available as required.
General comment	It is a very loaded question! No-one will disagree with the premise that you wish to improve the service.
Comment re Bridgend service	Yes, we feel the service was much better previously. The Bridgend Service was fantastic.
Comment re Bridgend service	The Bridgend Service was significantly better, providing excellent services to me and my family.
Comment re Bridgend service	I understand more about issues facing the service Really disappointed that the cochlear implant service was removed from the Princess of Wales Bridgend. The Heath is not easily accessible I feel like the service is being diluted and isn't as comprehensive as it used to be.
General patient position	I am currently happy with the care I receive from UHW/Cardiff but fully understand the issues with the current service. My only concerns are accessibility, communication for my own future CI journey.
General patient position	I was fitted with my BAHA at the QE Hospital 10+years ago in Birmingham. When I moved to South Wales in 2017, I went to Audiology at Gwent Hospital a few times for re-programming as I was experiencing problems. At this time, I had a hearing aid for my other ear. I have recently had a letter from QE Hospital Birmingham to inform me that my device is now obsolete. I have an appointment on the 27/01/2023 at Gwent Hospital to address this problem.
General patient position	After being referred to ENT, I was initially told I did not fulfil the requirements for Cochlear Implant, was referred to the Coach Trial - who declined me and said I was eligible for Cochlear Surgery!! What a roundabout!! As soon as I saw a different ENT Surgeon everything went very smoothly.
General patient position	Not really, but having an implant changed my life and I am eternally grateful. THANK YOU.

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General patient position	I am currently waiting for surgery to remove painful and swollen skin around implant - I was placed as Category 2 for surgery in September 2022. I am still waiting and
	currently on antibiotics for infection - it is vital I have surgery; my fear is when will this happen?
General patient position	From my experience as a deaf person, it was important for me to have familiar staff who I knew well and trusted, therefore a more family type atmosphere, easily accessible.
Specific patient position	My hearing has fallen rapidly in recent years and I would assess my hearing as only being around a 5 - 10 on a scale of 100; whereas with my BAHA I would estimate my hearing to be an 85 - 95. To this end I am scared of losing my BAHA (it can easily be knocked off) and therefore, selfishly, hope that future services will be in my locality should I have some sort of problem. I know that I could not cope without the BAHA.
General	Had my BAHA operation in 1992 with Mr Phillips of The
patient position &	Welsh Hearing Institute. I was the 7th person to have the operation. Before COVID started, I was seen at the
service	hospital once a year for a check-up, which I was always
feedback	glad of. So I knew there was no infection with the scar in my skull. We no longer get that treatment now.
Service feedback	No - just trying to make an appointment with Audiology, messages not passed on.
Service	I feel those working in this area should have at the very
feedback	least basic sign language skills.
Service feedback	The treatment I receive is very good. Staff brilliant.
Service feedback	The local service provides timely and effective care. Continuity of patient and specialist relationship is important. I am known to the service by name and not just a NHS number.
Service feedback	I have high confidence
Service feedback	I would like to place on record the contribution to cochlear implant hearing service made by Heidi Williams at University Hospital of Wales, Cardiff. She is an immense credit to the service.
Service feedback	The lack of qualified staff for the demands. The long waiting times involved.
Service feedback	Yes I do. The wait for cochlear implant was long and I had a complication after surgery, which could not be resolved by the operative time. This was very frightening indeed! The Team was not accessible, and they should have been.

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C:	I feel the same The massived forms the CI Teems at Countiff
Service feedback	I feel the care I've received from the CI Team at Cardiff (UHW) have achieved all the above.
Service feedback	There is NO service for specialist skills to remove implant for MRIC for comer [?coma] patients in South Wales.
Service feedback	My experience of the team at the Heath hospital has been excellent
Service feedback	This depends on better communication access - I had to fight for live professional captions for a remote consultation. Meeting communication needs must be a priority and not a battle!
Service feedback	Have doubts about equitable service from my personal experience. At my initial appointment, I immediately knew that I was not going to be referred for surgery from the consultant's attitude and apparent lack of interest. Fortunately, it all changed when I saw the ENT Cochlear Surgeon.
Service feedback	Adults should have better support and more therapy.
Service feedback	The standard of service keeps improving and I am pleased with the service I have received.
Service feedback	My daughter who is 4 has received outstanding care and support through the process of having her cochlear implants 2 years ago.
Service feedback	It would be ideal, if you could provide enough support for Adults, as children get plenty of support and therapy. But I was so struggling on my own. It took time for me to get used to it. Important to ask adults what they do seek from you and give your options of support to adults. Also, staff need to learn basic BSL, just in case. And especially reception staff are awful. They look down at the system whilst talking to us. How rude.
Service feedback	My treatment was 100% professional and caring.
Service feedback	The professionals doing this work know what they do and know best; they are second to none.
Service feedback	I have always been pleased with the service for my sister and would be willing to go wherever is convenient for the staff. We are so grateful for all their help.
Service feedback	As an implanted adult I am happy to continue with the service from Cardiff Heath Hospital.
Service feedback	I understand the need for a single implantable device hub for children and adults with an outreach support model but am concerned at the level of service that will be provided having experienced a deterioration as a consequence of moving from Bridgend to UHW.

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Service feedback	No proper instructions on how to use the kit provided. I am 84 and my wife who has a Cochlear Implant is 83. And so getting to the Heath Hospital would be very testing. It is also hard by telephone to get to the Cochlear Department to order spares to batteries.
Service Feedback	I think if we could converse/relay our problems to an accessible Audiologist quickly it would take away some of the panic one seems to suffer if we have a problem with our aid. Because it is such a life dependency item. Also a specialised hub would be solely beneficial for us patients. I actually waited 7 years in between my upgrade of my aid.
Service feedback	If my experience is that a change would be not needed to improve the service and attention I received when I was attended to. Thank you.
Service feedback	For myself I would simply like a conversation regarding the problems I have with my BAHA. An expert whose input I would value.
Service feedback	Would it still be the personal service I have now? I have already moved from Bridgend with no choice or option. Cardiff has been very good to me. A service that I have quick access to if I have a problem with my cochlear implant.
Service feedback and offer of patient voice	Any change for the deaf and hard of hearing would be amazing! The BAHA team do amazing work and to have a unit would be a great help to the team and patients. The difference the NAHA service has made to my life was that I can still work and enjoy life and not live in the "quiet world" feeling patronized. There is still a long way to go for a better understanding of the effects of loss of hearing and disability. Mr Williams and his team do amazing work, it transforms lives. So anything that can benefit research, funding and a specialist unit would get my support and am available if you need a "voice" to help.
Service feedback	Timely access to surgery: In my case, this is not happening. Category 2 patient seen by surgeon who implanted the new cochlear implant. Still waiting for surgery.
General comment	Availability of workforce. Easy access. Parking.
General comment	There are less patients with BAHAs than I expected
General comment	ease of access and good communication with clinicians is a key issue
General comment	I can understand it but needs some more organisation and regular dates.

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General	I could understand that in smaller areas around wales,
comment	would also have a smaller amount of patients compared to a big area such as Cardiff. I do understand that in
	smaller areas may have less qualified specialists/doctors
	in the area.
General	Having somewhere local and tidy somewhere service as
comment	everywhere else would be a bonus. Many people have
	recommended this but I have a awaiting a second
	option in May 2023
General	I work as a Stakeholder Lead for an NHS organisation
comment	undergoing a Transformation Programme to determine a
	Future Service Model. Totally appreciate all the issues
	facing the service and they are very relatable.
General	I understand more about issues facing the service
comment	
General	No privatisation of services should take place.
comment	
General .	Don't sink to the standards of QA Hospital Portsmouth!
comment	There and dischart as able to accompany to the control of the cont
General	I have a dedicated cochlear support nurse
comment General	As long as I and others can get the help we need
comment	As long as I and others can get the help we need.
General	It's difficult to achieve a cost effective process balancing
comment	the needs of a small percentage of the population.
General	Like all new ideas obviously we need to find out in
comment	practice.
General	Years ago, when my son needed his operations the
comment	waiting lists were quite long & funding was difficult. It
about the	seems better that these issues are less now.
service	
General	Future patients able to be referred to hearing Implant
comment on	centres by their doctors or consultants for further
the service	assessments.
General	I have used hearing implant more than five years and I
patient	can feel better using hearing implant (Cochlear Implant
comment	System).

#### **COMMENTS ON PROCESS & OPTIONS**

Alternate option	I also agree with Option E as well as Option D. Option D appears to be better than Option E because it has an outreach support model.
Alternate option	Option B

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Feedback on form – demographic information	My National Identity is Scottish (Scottish tick box missing on DB so I couldn't add this!)
Patient numbers	In table1 Referral's there seems to be enough numbers for cochlear implants and bone conduction hearing implants to meet the criteria for number of patients per surgeons?
Patient	I find the low level of patients described in this
numbers	document difficult to accept.
Process	I can't criticise it (process) and I can't say no.
Process	The process followed appears to have been a fair consideration of the views of all parties involved.
Process	I understand the processes but it is always best for everything to be started asap.
Process	Robust and comprehensively/clearly explained.
Process	This could and should have been resolved by now, but putting CI and BCHI has complicated matters. These are different devices for different populations with different needs. The ongoing situation has put enormous strain on the service and staff.
Process	The cochlear implant service has been working under 'urgent temporary arrangements' for three and a half years
Process	Perhaps some patients could have been included in this process.
Process	As stated the preferred option is not the preferred option of those working in the field with clinical knowledge of the needs of the service. Please reconsider with this pertinent information in mind.
Process, timescale and suggestion to split Cochlear and BCHI Separate children and	The service needs to be established, as a single centre for cochlear implants in south wales - the talks of mergers has been ongoing for too long. By trying to add in Baha now against clinical judgment it is adding a complexity needlessly.  I would rather have an Adult Hub separate from children.
adults	Positive for the CI convice removing uncertainty and
Separate Cochlear and BCHI	Positive for the CI service, removing uncertainty and allowing the service to move forward. For BCHIs, it will mean that patients will need to travel further for a simple surgical procedure, for no good reason.
Separate Cochlear and BCHI	Detriment to the service provided to both CI and BAHA patients. The needs of patients is not equitable and trying to lump them together will not be in the best interests of the service.

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Separation of BCHI and Cochlear	I agree that a single hub is appropriate for CI. I do not think it is necessary for BCHI, although it depends what exactly the proposal is. A centralised MDT could be helpful, but it is unnecessary to make patients travel large distances for such a simple surgical procedure.
Separation of BCHI and Cochlear	I do not think it necessary for all BCHI surgeries to be carried out in one hospital. The team who 'independently' assessed the situation and recommended one hub for BCHIs do not even run their own service this way, with surgeries carried out in several hospitals.
Separation of BCHI and Cochlear	The CI service has been working under temporary arrangements for a long time. This needs to be resolved as it is impacting planning and service development. There is no question that the CI service needs to be in one centralised hub, but the BCHI is not so clear-cut. Putting them both together is just prolonging the difficult situation facing the CI Service. BCHIs require a much simpler surgical procedure and provide a different way of amplifying sound, but the listening experience is essentially the same as with a conventional hearing aid. CI surgery is much more complex and carries more risks. The way sound is delivered by a CI is entirely different to a hearing aid/BCHI and patients need to learn to listen in a different way, which causes physical changes in the brain. This is why additional rehabilitation is needed. The needs of CI and BCHI patients and the services they require are very different. I'm not sure that WHSSC fully understands the differences.
Separation of BCHI and Cochlear	It is an unnecessary complication to include bone conduction devices. Not all bone conduction hearing aids require surgery yet have similar requirements for follow up and serve a similar population. The follow up required for Cochlear implants is significantly different, requiring users to adapt to an electronic rather than an acoustic signal.
Separation of BCHI and Cochlear	1) We support the preferred option for CI services in South Wales. 2) However, it is not possible to form a view on the preferred option for BCHI services, as there is insufficient evidence presented to support the case for change. It should also be noted that there are BCHI services based within Audiology services in NHS England which operate effectively, with clear cross referral pathways to tertiary services where required.

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Separation of children and adults	I do feel that when patients are separated into children and adults, staff can maybe specialise more easily.
Suggest split Cochlear and BAHA –	Cochlear Implant Services do not need to be grouped with BAHAs. They are very different and do not require the same care pre or post operatively. Trying to merge services in this way will be of detriment to patient care. The consultation process sought the views of professionals working within the field and yet you admit in the paperwork that their clinical opinion has been ignored.

#### **WAITING TIMES**

Waiting lists	If waiting lists and funding are long then the longer it takes for the person to adjust to the implants, causing further issues.
Waiting times	I am wondering if this will have a positive impact on waiting times.
Waiting times	Only issue I have is I am not seen for 12-18 months.
Waiting times - non specific	Waiting times for appointments
Waiting times and resources	As stated earlier, I think there would be an increased amount of patients heading to one location which in turn will have an increase of wait time is the main concern of mine. I do think the positives is that financially, it could all go into one hospital which would be able to cater for all departments.

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# The Future of Specialist Hearing Implant Device Services in South Wales Questionnaire

We are seeking the views of patients and other members of the public about how specialist hearing implant device services, such as Cochlear Implants and Bone Conducting Hearing Implant (BCHI) are delivered in South Wales. Your contribution to this is valuable, and helps us shape future discussions. If easier for you, you can complete this questionnaire on-line (at <a href="https://forms.office.com/r/s8bSYTaU5K">https://forms.office.com/r/s8bSYTaU5K</a>)

Please tick one circle for each question.

#### Section 1: Please tell us about yourself

- 1. Are you responding on behalf of a group/organisation or as an individual?
  - Group/Organisation (please state which group or organisation and move to question 7)

Audiology Standing Specialist Advisory Group / Audiology Heads of Service Group

O Individual

#### 2. What is your age?

- O Under 16
- 0.16 18
- 0 19 49

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0	Prefer not to say
3. What	is your gender?
0	Female
0	Male
0	Non-binary
0	Prefer not to say
l. How v	vould you describe your national identity?
0	Welsh
0	English
0	Scottish
0	Northern Irish
0	British
0	Other
0	Prefer not to say
5. How v	vould you describe your ethnic group?
0	White
0	Mixed or multiple ethnic groups
0	Asian, Asian Welsh, Asian British
0	Black, Black Welsh, Black British, Caribbean or African
0	Other
0	Prefer not to say
Dlance	tell us the first four characters of your postcode. (This
	us learn where the answers have come from)
	us learn where the answers have come from)

O 50 – 69

O 70+

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#### 7. Which Health Board area do you come under?

- O Aneurin Bevan University Health Board
- O Betsi Cadwaladr University Health Board
- O Cardiff & Vale University Health Board
- O Cwm Taf Morgannwg University Health Board
- O Hywel Dda University Health Board
- O Powys Teaching Health Board
- Swansea Bay University Health Board
- O NHS England
- O Other

#### **Section 2: About the Service**

#### 8. As a result of reading this information:

- O I have a better understanding of how Cochlear Implant and BCHI services are currently <u>organised</u>
- O I have no understanding of how Cochlear Implant and BCHI services are currently <u>organised</u>
- My understanding of how services are currently <u>organised</u> is the same:

#### 9. As a result of reading this information:

- $\bigcirc$  I have a better understanding of the <u>issues</u> facing the service
- O I have no understanding of the issues facing the service
- O My understanding of the issues is the same

#### Do you have any comments about the issues facing the service?

The paper does not reflect the significant workforce issues and challenges faced by the Cardiff Cochlear implant service as a result of the Bridgend service being suspended since August, 2019 (due to workforce fragility issues). We understand that funding is still being allocated to CTM for staffing despite only one member of staff from Bridgend working on the CI programme on a part time basis.

The Cardiff and Vale UHB (C&V UHB) Audiology service do not currently have the required estate to see all patients for cochlear implant and BCHI assessments, as

there needs to be a sufficient number of large sound proofed room facilities. This situation has impacted on the current service to patients delivered by C&V UHB. The cochlear implant service issues remain unresolved and the addition of BCHI into the engagement has increased the delay of any decision around funding for the CI service at C&V UHB. As a result of unresolved workforce issues, the service at C&V UHB is now vulnerable due to staff sickness and stress. There now needs to be a clear plan around workforce and accommodation. Failing this, it is highly likely that there will be a subsequent collapse of the C&V implant service.

#### 1) Minimum numbers for BCHI

- a) Section 6 states that 'guidance on <u>standards</u> for bone conduction hearing aids require centres to perform at least 15 procedures per year'. Although the paper then references the commissioning policy from which this minimum number has been quoted with a bookmark, the reference to standards is misleading.
- b) The minimum number quoted in the English commissioning policy has been obtained from professional consensus reached in 1998. It is not clear therefore that this is relevant to services today given the policy, technology and workforce changes that have occurred in the last 24 years.
- c) The commissioning policy referred to in the engagement paper is not the latest version of this policy and appears to have been superseded by NHS England 16041/P (england.nhs.uk) which does not refer to minimum numbers and does reference a more contemporary clinical consensus on standards again with no reference to minimum numbers.
- 2) The paper does not explain what outcomes are not being met by the current service structure i.e. what requires change and improvement.
- 3) The paper describes that an implant MDT needs to provide all types of implants. This is not true. CI services need to offer all implants, but the bone conduction commissioning document does not state that BCHI centres have to offer any other devices. This statement in the engagement paper is presumably based on the assumption that the MDT must be a joint CI/BCHI MDT. There are no standards or recommendations for this model, and this is not the model found in most BCHI centres in the UK. The most recent Clinical Commissioning Policy, NHS England 16041/P does not reference a joint MDT but only requires that the MDT must consider which implant is the most suitable for each patient which can be achieved without a single MDT for all implantable devices.
- 4) In the referenced Clinical Commissioning Policy, section 7 (Epidemiology & Needs assessment) it states that 8-10 BCHI per population of 300,000 is the estimated activity in England and this would translate to in the region of 100 BCHI per year in Wales; of which 75% would be in South Wales. This suggests that there is a large unmet need for this intervention in Wales which may present following removal of 'capped funding' for these devices. Based on meeting the recommended numbers of BCHI fittings there would be sufficient

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numbers for multiple centres in South Wales to meet the minimum stated in the NHS England CCP.

ASSAG therefore concludes that the population is underserved, and the recommendation would be to reinforce existing services for BCHI and enable them to meet unmet demand and through agreed National pathways for referral. This would solve the problem of minimum numbers and safety without creating additional barriers for patients.

- 6) The paper states that a large number of patients would be required to adopt new technologies. Adoption of new technology could be adopted for example middle ear implants could be adopted at a centralised CI service without requiring BCHIs services to be centralised also. Separate BCHI services does not prevent the adoption of new BCHI technologies and so this is not considered to be a case for change.
- 7) The paper states that a centralised service would deliver an improved service comparable to other regional centres. This would suggest that the services are not currently comparable to those regional centres but does not specify what the differences are. It also makes an assumption that the existing regional services are better than any local services but there is no evidence in the paper for this assumption.

There is no reference related to the statement that procedures carried out at larger centres result in better outcomes.

### 10. Would you agree/disagree with the following aims for a future Cochlear Implant and Bone Conduction Hearing Implant service:

#### The service:

- can deliver a safe and sustainable hearing implant device service for the adult and children in South Wales
- has equitable access
- meets national standards
- has staff in the right place with the right specialist skills
- facilitates timely access to surgery
- Agree
- Disagree
- O Neither agree or disagree

We agree with the aims for the service however wish to make it clear that

equitable access should include distance, travel and cost as well as waiting times.

The paper mentions that some people may not have to travel as far as they do now. As it seems unlikely that any site other than Cardiff would be chosen for the centralised service, we are not aware of any circumstances under which travel to a centralised service would be reduced compared to the current situation

#### 11. As a result of reading this information:

- O I have an understanding of the <u>process</u> that has been followed to arrive at the preferred option
- O I have no understanding of the <u>process</u> that has been followed to arrive at the preferred option
- Not applicable

Do you have any comments about the process followed?

- 1) This question does allow for responders to have a partial understanding.
- 2) It is not clear in the engagement paper which external implantable device centre was chosen to complete the evaluation, what service model is delivered at that centre, why they were chosen or whether stakeholders in that region were also asked to contribute to the evaluation. Evaluation by a single centre could inadvertently have introduced bias into the evaluation. There are two models of bone anchored hearing aid delivery in England. One is single auditory implant centre of which there are 16 in England and the other is a standalone bone anchored hearing aid centre within an audiology centre of which there are over 100. What assurance is there that both models have been consulted?
- 3) The process does not seem to have considered the Welsh context in which services have run, specifically the current development of All Wales implantable device standards and the close working relationships of all centres in Wales.
- 4) There is some incorrect information in the engagement documents, which will affect the validity of this engagement process, specifically:
- a) In the slide summary (slide 10 of the English version) it states that appointments before the hearing implant and after the hearing implant has been programmed and fitted will take place closer to home. This is factually incorrect for CI and may not be possible for BCIG depending on the outcome of the pathway design.

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b) In most versions except the core document, eg slide 7 of the English slide summary, is the statement *British Cochlear Implant Group (BCIG) say that Consultants should undertake a minimum of 10 cochlear implants per surgeon, and that a centre should undertake a minimum of 15 BCHI per year. There are not enough patients to support this across multiple centres.* This is factually incorrect. ASSAG would be concerned that the significance of this statement to the case for change may make the engagement invalid.

# 12. Please tell us what you think about the preferred option of a single implantable device hub for both children and adults with an outreach support model.

- I agree with the preferred option
- I disagree with the preferred option
- O I have no particular view on the preferred option

Do you have any comments about the preferred option (i.e. why you agree/disagree)?

- 1) There is no option to partially agree with the preferred option
- 2) It is not possible to provide a final opinion of the preferred option without more information on the specific models being proposed. It is not clear in the engagement paper what the services will look like and the advantages and disadvantages of each model.
- 3) Cochlear Implants

A single site for CI in South Wales would resolve the current and urgent issues facing the cochlear implant service. It would allow for sustainable workforce planning and the development of a full and specialist MDT within the service. Travel for some patients will unfortunately be increased compared to the two-centre model previously provided but this would be balanced by the ability to invest in the best staff, equipment, and facilities at a single centre.

The other advantage of the CI team would be to assist in the robust and efficient management of the cost of this service. This also fits with the model being provided in England. Our view is that middle ear implants would generally fit within an auditory implant programme as per the English model rather than in a standalone centre.

4) For bone conduction implants the advantages of a single centre are less clear.

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There is ample precedence of safe and effective standalone centres working within audiology services for bone anchored hearing aids in England with clear cross referral pathways to a tertiary implant centre where required. There are no standards requiring bone anchored hearing aids to be done in large regional sites or for services to be provided only in those providing other implantable hearing devices.

With regards to the creation of a single MDT the advantages of including bone conduction implant services in a single centre **may** provide additional staff resilience and promote the consideration of potential for middle ear implants however, there is no evidence that this is currently or foreseen to be an issue and it is not required in any recent policies or professional consensus. If bone conduction services remain standalone, then the recommendation would be for mitigations and safeguards such as joint MDTs for patients meeting the criteria for more than one type of device (likely to be very few) to ensure equitable access.

The disadvantages of a single centre are the increased travel and cost for patients which ASSAG do not feel are balanced by any advantages for patients requiring this type of device.

## 13. If the preferred option was progressed, what do you think the impact would be?

- 1) The impact of the preferred option for bone conduction hearing aid patients is of decreased access, particularly as the level of service to be provided in centres 'closer to home' is not defined in the paper.
- 2) The impact of the combined MDT which allows for all options to be offered to patients is not obvious as, patients who are candidates for bone conduction hearing aids are generally not candidates for cochlear implantation and vice versa. Robust cross referral pathways are the norm across multiple disciplines in the Welsh NHS.
- 3) The impact on quality and outcomes of a centralised service for BCHI's is not clear as the issues and required quality improvements required are not clear in these documents particularly as BCHI surgery is significantly less complex than that of cochlear implantation.
- 4) A move to one centre would require significant investment in facilities, for example large sound-proof clinical rooms, to avoid an ongoing detrimental impact on the core audiology service. This would require a significant capital investment. The need to provide for both CI and BCHI on a South Wales basis may impact on the site's ability to provide the facilities required for CI.

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5) Removing the BCHI service from Swansea Bay UHB may have an impact on the South Wales microtia service, as the advice of surgeons with knowledge of BCHI placement and surgery is important in the management of Microtia.

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### **ANNEX B - GLOSSARY OF TERMS**

Audiology	The branch of science and medicine concerned with the sense of hearing.
Specialist Audiologist	A Specialist Audiologist specialises in the diagnosis, analysis and treatment of human auditory disorders such as hearing, tinnitus and audio balance deficiencies.
Bone Conduction Hearing Implant	A Bone Conductor Hearing Implant (BCHI) is a hearing aid which uses bone conduction to help sound get to the inner ear. Note many people also call a BCHI a BAHA.
Clinical Child 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
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.
Hearing Therapist	A Hearing Therapist offers counselling to help with hearing difficulties
Multi-Disciplinary Team (MDT)	A Multi-disciplinary Team is a mixture of team of named healthcare professionals (eg Doctors, audiologists, nurses etc) who are responsible for discussing and arranging facilitating communication and coordinating care for patients.
National Institute for Health and Care Excellence (NICE)	National Institute of Clinical Excellence – sets standards and guidance for services
Paediatric Anaesthetist	Paediatric Anaesthetists are responsible for the general anaesthesia, sedation, and pain management needs of infants and children

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Qualified Teacher of the Deaf (QTOD)	Qualified Teachers of the Deaf (also known as QToDs) are qualified teachers who provide support to D/deaf children, their parents and family and other professionals who are involved with a child's education.
Specialist Nurses	Specialist Nurses are dedicated to a particular area of nursing; caring for patients suffering from long-term conditions and diseases.
Specialist Radiologists	Specialise 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.
Speech and Language Therapist	A Speech and Language Therapist provides life- changing treatment, support and care for children and adults who have difficulties with communication, eating, drinking and swallowing.

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Report Title	Performance N	Management I	ramework	Agenda Item	3.7	
Meeting Title	Joint Committ	ee		<b>Meeting Date</b>	16/05/2023	
FOI Status	Open					
Author (Job title)	Assistant Direct	or of Planning				
Executive Lead (Job title)	Director of Planning & Performance/Director of Finance & Information					
Purpose of the Report	The purpose of this report is to present the draft WHSSC Performance Management Framework approach which subject to approval will be embedded into WHSSC's business as usual processes, and shared with provider organisations, for transparency and awareness.					
Specific Action Required	RATIFY	TIFY APPROVE SUPPORT ASSURE INFORM				

### **Recommendations:**

Members are asked to:

- **Note** the report,
- **Approve** the proposed approach for an updated WHSSC Performance Management Framework; and
- **Support** the proposed implementation arrangements.

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### WHSSC PERFORMANCE MANAGEMENT FRAMEWORK

### 1.0 SITUATION

The purpose of this report is to present the draft WHSSC Performance Management Framework approach which subject to approval will be embedded into WHSSC's business as usual processes, and shared with provider organisations, for transparency and awareness.

### 2.0 BACKGROUND

During the COVID-19 pandemic, ministerial permissions were granted for the relaxation of performance management across NHS Wales. WHSSC responded to the request for a relaxed framework by:

- A) Relaxing the formal focus of SLA meetings (reporting and assurance on contracts, activity and cost) to a less formal approach (reporting on recovery, anticipated trajectories, and general ) updates; and
- B) Moving traditional service level performance management meetings to commissioner assurance meetings.

On the 7 September 2021, the Joint Committee approved a new Commissioning Assurance Framework (CAF) and approved the following supporting documents:

- · Performance Assurance Framework,
- Risk Management Strategy,
- Escalation Process; and
- Patient Engagement & Experience Framework.

Since then there has been a further period of tolerance as the system has moved from crisis into recovery, and financial frameworks moved from block back to being based on activity and performance.

Alongside Welsh Governments (WGs) shift back to a robust performance management approach, WHSSC has also signalled its intention to do likewise, and now needs to recalibrate its performance management arrangements, redefine the roles and responsibilities of differing parts of the performance management system; and bring standardisation across performance management levels with all providers, and ultimately re-develop the performance management framework.

### 3.0 ASSESSMENT

### 3.1 Performance Context

On behalf of the seven Health Boards (HBs) in Wales, WHSSC has a responsibility to commission services of the highest quality for the best cost for the welsh population.

It is committed to the prudent use of resources, and value based commissioning.

### 3.2 Performance Structure and Principles

### 3.2.1 Principles

WHSSC's Performance Management arrangements are driven by the following principles that:

- Demonstrate clear expectations of ourselves and providers with regards performance management,
- Demonstrate behaviours aligned with WHSSC values with an emphasis on continual improvement,
- Enable a balanced scorecard approach, aligning quality, cost and performance,
- Enable openness and transparency as related to the commissioning of specialised services for the welsh population,
- Enable commissioning of services to the highest quality for the most effective cost (Value based commissioning),
- Enable scrutiny and assurance of commissioned services (both quality and cost),
- Enable clear processes for risk and escalation,
- Offer opportunities for re-commissioning where necessary based on a) nonperformance b) creating a richer market; and
- Has a clear thread across all levels of its hierarchy with well-defined roles and responsibilities at each level

### 3.3 Performance Management levels

There are 3 levels at which performance management discussions between WHSSC and provider HBs take place, and upon which the Performance Management arrangements have been built: Strategic, Planning and Performance. The performance framework hierarchy is outlined below:

Level of discussion	Meeting	Purpose
Strategic	Board to Board Exec to Exec	<ul> <li>Strategic direction</li> <li>Strategic risks</li> <li>Strategic appetite for service developments</li> <li>Strategic discussion on population health, equity, access etc.</li> </ul>

Performance Management Framework

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Level of	Meeting	Purpose		
discussion		- III III		
		Enabling delivery		
Planning	Planning team to HB corporate teams	<ul> <li>Monitor progress with development of Integrated Commissioning Plan (ICP) and Integrated Medium Term Plans (IMTPs) Identify barriers/risks to implementation of plan and developments contained therein</li> <li>Share intelligence in order to triangulate workforce, finance and performance improvement</li> <li>Ensure there are 'no surprises' on performance and delivery issues</li> </ul>		
Performance	SLA Meetings	<ul> <li>Formally manage and escalate variation in performance on quality, activity, delivery of Ministerial measures and financial performance.</li> <li>Formally receive exception reports on services in Escalation</li> <li>Deal with issues escalated from the service level performance meetings</li> <li>Formally note and monitor investments and benefits</li> </ul>		
	Service level performance meetings	<ul> <li>To monitor performance in individual service areas – including quality, activity, Ministerial and service specification measures and financial performance</li> <li>To monitor investments and benefits</li> <li>To escalate issues as needed to the SLA meeting with Health Boards</li> </ul>		
	Escalation	To enable development of an action plan for those services in escalation		

Performance Management Framework Page 4 of 8

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Level of discussion	Meeting	Purpose				
		•	nece	enable essary action nable de-e		of

A more detailed understanding of the performance element in particular can be seen here:

### **SLA Meeting**

**Exec level WHSSC/Corporate HB meeting** Review against overall HB contract (both quality, activity, access & cost)

- Monitoring driven by data
- Issues escalated from performance management and Comm teams

Cancer /Blood Perf Mgt

Cardiac Perf Mgt

Intestinal Failure Perf Mgt Mental Health Perf Mgt

Neuro Perf Mgt W&C Perf Mgt

#### WHSSC/Service meeting

- WHSSC monitor commissioned service
- Commissioner Assurance on quality, delivery, variance and resource utilisation
- Opportunity for discussions on service developments/recommissioning

Cancer /Blood Comm Team

Cardiac Comm Team Intestinal Failure Comm Team

Mental Health Comm Team

Neuro Comm Team W&C Comm Team

**Internal WHSSC mechanism** to bring together planning, commissioning, quality and cost in order to enable full virtual commissioning team. Discuss issues, risks, progress, variance and development opportunities

### 3.4 Development of a performance management framework

A full performance management framework has been developed which sets out the approach, how it has been developed and how it will be embedded. The framework is attached at **Appendix 1.** This updated framework will replace Appendix 1a in the CAF endorsed in September 2021.

# 3.5 Development of a performance management toolkit (enabling standardisation)

The framework is supported by a suite of templates/documents that aim to bring standardisation to the approach. This is attached to the framework, and can also therefore be located in **Appendix 1**.

### The toolkit includes:

- Schedule of meeting dates across the year,
- Mandate/Terms of Reference/membership for each group
  - TOR Board/Joint Committee,
  - TOR Exec to Exec,
  - TOR Planning Interface Meetings,
  - TOR SLA Meetings,
  - TOR Service Performance Management Framework,
  - TOR Commissioning Teams,
- Agenda templates for each group
  - Agenda Board/Joint Committee,
  - Agenda Exec to Exec,
  - Agenda Planning Interface Meetings,
  - Agenda SLA Meetings,
  - Agenda Service Performance Management Framework,
  - Agenda Commissioning Teams,
- The Escalation framework; and
- Example data pack to drive discussions at SLA and service level performance meetings.

### 3.6 Appropriate level of operation

During the past 3 years, as roles and responsibilities of groups and individuals have changed, the role and purpose of some of the groups may have a) morphed to fulfil alternate roles b) become broader that their original purpose / membership; C) taken on a different level of operation than originally intended. It is important that this recalibration, seeks to clarify the appropriate and necessary level of operation of each of the component parts within the framework and to ensure that appropriate membership is there, whilst being cognisant of calls on HB operational colleagues time. Proposed membership of each is contained within the suggested Terms of Reference (ToR).

### 3.7 Implementing the framework

### 3.7.1 Sharing across WHSSC

A number of colleagues have already seen an early draft of this report, however subject to the necessary changes and approval, it is suggested that the framework and supporting documentation is launched by the WHSSC Managing Director. A lunch and learn session for the organisation may also be delivered, and it is proposed that the Heads of Department meet after the first round of SLA meetings to assess impact, learning and further development.

### 3.7.2 Testing with providers

Informal discussions on the approach have thus far been held with providers. The approach has been welcomed, in particular clarity on the roles, responsibilities, membership and level of operation of each of the framework parts. We will work together with providers to understand impact of approach and seek to mature together over time. It is also suggested that the framework is shared at a forthcoming management team for discussion/awareness.

### 4.0 RECOMMENDATIONS

Members are asked to:

- Note the report,
- Approve the proposed approach for an updated WHSSC Performance Management Framework; and
- **Support** the proposed implementation arrangements.

Governance and Assurance					
Link to Strategic Objectives					
Strategic Objective(s)	Governance and Assurance Choose an item. Choose an item.				
Link to Integrated Commissioning Plan	Yes				
Health and Care Standards	Governance, Leadership and Accountability Safe Care 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 improved health and well-being with better prevention and self-management Choose an item. Choose an item. Choose an item. Choose an item.				
<b>Organisational Implicat</b>	ions				
Quality, Safety & Patient Experience	Re-establishing performance management arrangements will ensure that performance indicators are monitored to measure improvements in the quality of services and patient care.				
Finance/Resource Implications	There is no financial impact; however, there is a possibility that non-delivery of certain performance measures my result in financial or service consequences.				
Population Health	No adverse implications relating to population health have been identified.				
Legal Implications (including equality & diversity, socio economic duty etc)	The framework has been developed cognisant of the relevant legal implications				
Long Term Implications (incl WBFG Act 2015)	The framework has been developed cognisant of the relevant long term implications				
Report History (Meeting/Date/ Summary of Outcome	CDGB 06.03.23 Management Group 27.04.23 CDGB 02.05.23				
Appendices	Appendix 1 – Performance Management Framework and Performance Toolkit				



### **WELSH HEALTH SPECIALIST SERVICES COMMITTEE**

# PERFORMANCE FRAMEWORK FEBRUARY 2023

3.7 Appendix 1
Joint Committee - Performance Management Framework

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### **CONTENTS**

1	Introduction	3
2	Purpose	3
3	The Commissioning Cycle	4
4	Description of approach	5
5	Embedding the approach	8
	APPENDICES	
Α	WHSSC Performance Management toolkit	12

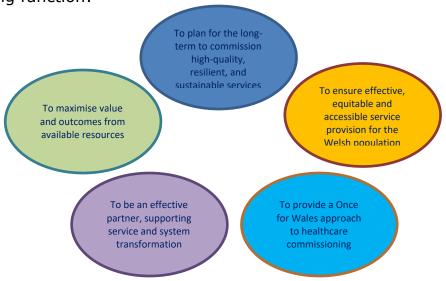
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#### 1. INTRODUCTION

On behalf of the 7 Health Boards in Wales, The Welsh Health Specialist Services Committee (WHSSC) has a responsibility to commission services of the highest quality for the best cost for the welsh population. It is committed to the prudent use of resources, and value based commissioning.

WHSSC aims to ensure that services are commissioned and delivered to a high quality, monitoring services regularly, and realising both value for money and service sustainability.

WHSSC seeks to pursue the following Strategic Objectives to fulfil its National commissioning function:



As a National Commissioner, WHSSC has responsibility to performance manage commissioned services and has therefore developed this framework to outline how it will fulfil its functions in this regard. We are committed to developing a compassionate and collective culture that is underpinned by effective performance management and a focus on improvement. We consider that effective performance management is the responsibility of every member of the WHSSC team.

### 2. PURPOSE

The purpose of the Performance Framework is to describe the organisation's system for ensuring effective commissioning including appropriate monitoring, performance management and escalation. Working on behalf of the 7 Health Boards in Wales, WHSSC has a duty to monitor and report on providers performance and ensure contracted services are delivered within cost, to the appropriate levels of activity and to the standard and quality set out within WHSSC service specifications. The Performance Framework is part of our wider governance framework which ensures our commissioning activities are undertaken in line with public sector accountabilities.

The development and communication of the Framework will act as a useful engagement tool to embed ownership of performance at every level within WHSSC, and also to

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articulate our performance management expectations from those we commission services from.

This document therefore sets out the performance management approach, including how it will operate and be embedded. Specifically it details:

- The Commissioning Cycle
- The WHSSC Performance Management Approach
- How the approach will be embedded
- Accountabilities
- Escalation

The framework is supported by a suite of templates (included as appendices) which aim to bring standardisation and commonality to the activities set out within this framework.

### 3. THE COMMISSIONING CYCLE

The Commissioning cycle sets out a range of activities associated with effective commissioning through strategic planning, procurement of services and Monitoring and evaluation. This framework concerns itself predominantly with the monitoring and evaluation activities, specifically; performance management; performance monitoring; performance reporting; and escalation.



### 4. WHSSC PERFORMANCE MANAGEMENT APPROACH

### 4.1 Principles

WHSSC's Performance Management arrangements are driven by the following principles:

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### Arrangements that:

- Demonstrate clear expectations of ourselves and providers with regards performance management
- Demonstrate behaviours aligned with WHSSC values with an emphasis on continual improvement
- Enable a balanced scorecard approach, aligning quality, cost and performance
- enable openness and transparency as related to the commissioning of specialised services for the welsh population
- enable commissioning of services to the highest quality for the most effective cost (Value based commissioning)
- enable scrutiny and assurance of commissioned services (both quality and cost)
- Enable clear processes for risk and escalation
- Offer opportunities for re-commissioning where necessary based on a) non performance b) creating a richer market
- Has a clear thread across all levels of its hierarchy with well defined roles and responsibilities at each level

### 4.2 Performance Management levels

There are 3 levels at which performance management discussions between WHSSC and provider Health Boards take place, and upon which the Performance Management arrangements have been built; Strategic, Planning and Performance.

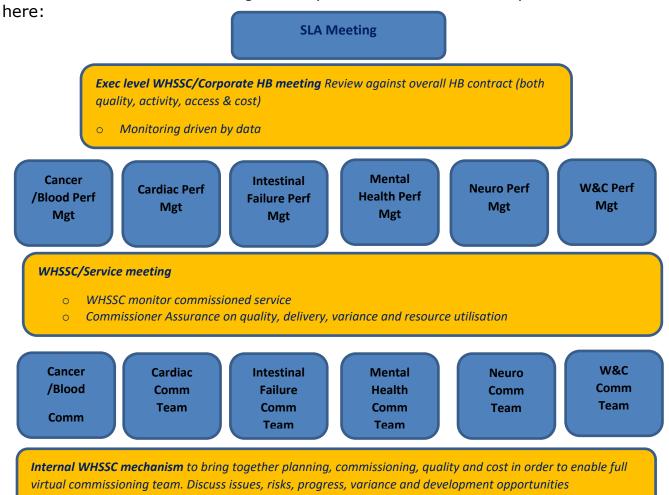
The performance framework hierarchy is outlined below:

Level of	Meeting	Purpose
discussion		
Strategic	Board to Board Exec to Exec	<ul> <li>Strategic direction</li> <li>Strategic risks</li> <li>Strategic appetite for service developments</li> <li>Strategic discussion on population health, equity, access etc</li> <li>Enabling delivery</li> </ul>
Planning	Planning team to HB corporate teams	<ul> <li>Monitor progress with development of ICP and IMTPs Identify barriers/risks to implementation of plan and developments contained therein</li> <li>Share intelligence in order to triangulate workforce, finance and performance improvement</li> <li>Ensure there are 'no surprises' on performance and delivery issues</li> </ul>
Performance	SLA Meetings	<ul> <li>Formally manage and escalate variation in performance on quality, activity, delivery of Ministerial measures and financial performance.</li> <li>Formally receive exception reports on services in Escalation</li> <li>Deal with issues escalated from the service level performance meetings</li> </ul>

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	<ul> <li>Formally note and monitor investments and benefits</li> </ul>
Service I performance meetings	<ul> <li>To monitor performance in individual service areas – including quality, activity, Ministerial and service specification measures and financial performance</li> <li>To monitor investments and benefits</li> <li>To escalate issues as needed to the SLA meeting with Health Boards</li> </ul>
Escalation	<ul> <li>To enable development of an action plan for those services in escalation</li> <li>To enable monitoring of necessary actions</li> <li>To enable de-escalation</li> </ul>

A more detailed understanding of the performance element in particular can be seen



It is essential for the performance arrangements to be effective, that clear terms of reference are established for all of the constituent parts. Attached to this paper therefore are draft terms of reference for the following framework groups:

- Board to Joint Committee meetings
- Exec to Exec meetings
- Planning Interface Meetings

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- Service Level Agreement Meetings
- Service performance management meetings
- Escalation framework

It is important that membership of the varying components is at the appropriate and necessary level of operation. Membership of each is therefore also contained within the relevant Terms of Reference. To guide suggested level of operation and discussion for each of the components, an outline agenda for each is contained within the supporting pack.

### 4.3 Performance reporting

A number of data sources will be brought together by the WHSSC Information team in order to inform performance management discussions. Reports will be prepared on overall WHSSC performance and presented to both Management Group and Joint Committee.

### 4.4 Escalation

Where there is variance with regard anticipated performance, WHSSC staff will work within the agreed escalation framework to support organisations to recover their performance position, enabling the development of an action plan; monitoring necessary actions and working towards a position of de-escalation. The escalation framework is also appended to this document.

### 5. EMBEDDING THE APPROACH

### 5.1 Values and Behaviours

WHSSC has a strong set of values that has been collectively developed by the team. They are as follows:



These values will be evident through our performance management approach as we work in partnership with others to ensure high value services are commissioned and delivered through improvement and innovation and with respectful enquiry that drives improvement and effective commissioning.

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### 5.2 Internal to WHSSC

Responding to our commissioner responsibilities, all WHSSC staff have a responsibility with regard performance management. As such this framework will be shared broadly with on-boarding sessions taking place for all staff at its acceptance, and with new starters as part of induction.

### 5.3 With providers

It is equally important that all providers are clear on the framework and there is transparency in its use. Informal discussions on the approach have thus far been held with providers. The approach has been welcomed, in particular clarity on the roles, responsibilities, membership and level of operation of each of the framework parts. We will work together with providers to understand impact of approach and seek to mature together over time. It is also suggested that the framework is shared at a forthcoming management team for discussion/awareness All WHSSC colleagues should be familiar with the key messages presented by information colleagues in readiness for discussions on their own service areas at various stages of the performance management framework. A sample pack is contained within the supporting pack.

### 5.4 Roles and responsibilities

Whilst performance management is everyone's responsibility within WHSSC, bringing clarity to key functions is considered essential for the process to be effective, and ownership to be clear.

**Joint Committee** – Joint Committee are ultimately responsible for the Governance of WHSSC setting the strategic direction and holding responsibility for approving the Integrated Commissioning Plan. Members of the Committee have concern with the matter of performance management and reporting such as to ensure the commissioning and delivery of high quality services for the population of Wales. Regular performance reports are presented here.

**Management Group -** Have regard performance management of specialised services, as a delegated group acting on behalf of Joint Committee they have regular reports presented, and have the opportunity to work alongside WHSSC colleagues in order to scrutinise/deep dive on issues of concern or escalation.

**Senior Responsible Officer** – The Director of Planning and the Director of Finance are the Senior Responsible Officers for the Framework. The Director of Planning will lead the development and implementation of the Performance Framework and has delegated responsibility for preparing, implementing and updating this. The DOP will also ensure that systems are in place for the measurement of national and local measures and KPIs which are reported via the Dashboard(s). The Director of Finance will ensure Performance Reports are produced for scrutiny and assurance by CDGB and the Board. The Director will ensure that these include transparent reporting of areas of good progress as well as areas of performance that require attention and/or escalation. The WHSSC team will implement the Framework by:

- ensuring the performance cycle is maintained and reporting requirements are met.
- working with services, in partnership to develop the KPIs, Dashboard and Reports.

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• working with services, in partnership with others, to undertake targeted work to improve performance as required.

**Information & Data –** The WHSSC information team are responsible for the collation of data and presentation of information

**Finance and contract monitoring information** – Financial and contract monitoring information will be provided by the WHSSC finance team

**Quality & patient safety** – Issues of patient safety and quality will be provided and reported on by the WHSSC Quality and Patient safety team

**Planning & Service development –** Service development and planning activities will be undertaken by members of the WHSSC planning team.

### 5.5 Performance Management Toolkit

A suite of documentation has been developed in support of these arrangements, and can be found in the toolkit appended to this framework. It includes:

- A schedule of the dates across the year
- A proposed Mandate/Terms of Reference/membership for each group
- An outline agenda for each group
- An example data pack to drive discussions at SLA and service level performance meetings
- The Escalation framework

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### **APPENDIX A**



### **WELSH HEALTH SPECIALIST SERVICES COMMITTEE**

PERFORMANCE FRAMEWORK
TOOLKIT
FEBRUARY 2023

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### **CONTENT**

1	Schedule of meeting dates across the year	15
2	<ul> <li>Mandate/Terms of Reference/membership for each group</li> <li>TOR Board/Joint Committee</li> <li>TOR Exec to Exec</li> <li>TOR Planning Interface Meetings</li> <li>TOR SLA Meetings</li> <li>TOR Service Performance Management Framework</li> <li>TOR Commissioning Teams</li> </ul>	20 21 22 24 30 33
3	<ul> <li>Agenda templates for each group</li> <li>Agenda -Board/Joint Committee</li> <li>Agenda - Exec to Exec</li> <li>Agenda - Planning Interface Meetings</li> <li>Agenda - SLA Meetings</li> <li>Agenda - Service Performance Management Framework</li> <li>Agenda - Commissioning Teams</li> </ul>	40 41 42 44 46
4	The Escalation framework	48
5	Example data pack to drive discussions at SLA and service level performance meetings	59

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Month	Oct	Nov	Dec	Jan	Feb	March	April	May	June	July	Aug	Sept	Oct	Nov	Dec
Strategic															
Exec to Exec			C&VUHB 5 <sup>th</sup> Dec CTMUHB 5 <sup>th</sup> Dec			CTMUHB 6 <sup>th</sup> C&VUHB 9 <sup>th</sup>						CTMUHB 4 <sup>th</sup>			
HB to HB		C&VUHB 24 <sup>th</sup>		SBUHB 11 <sup>th</sup>	PTUHB 7 <sup>th</sup>							CTMUHB 4 <sup>th</sup>			
Planning															
BCUHB Planning Meetings		8 <sup>th</sup>		10 <sup>th</sup>	14 <sup>th</sup>		11 <sup>th</sup>	9 <sup>th</sup>		12 <sup>th</sup>	8th		10 <sup>th</sup>	7 <sup>th</sup>	
C&VUHB Quarterly Planning Meetings			13 <sup>th</sup>			14 <sup>th</sup>			13 <sup>th</sup>			12 <sup>th</sup>			12 <sup>th</sup>
SBUHB Quarterly Planning Meetings		21 <sup>st</sup>			20 <sup>th</sup>			15 <sup>th</sup>			21 <sup>st</sup>			20 <sup>th</sup>	
Performance															
ABUHB <b>SLA</b>				18 <sup>th</sup>			24th			20th			12th		
BCUHB <b>SLA</b>			14th			22nd	23rd		21st			20th			
C&VUHB <b>SLA</b>		23rd		9 <sup>th</sup>		20th		11th		17th		18th		13th	
CTMUHB <b>SLA</b>		16th													
SBUHB <b>SLA</b>		10th			9 <sup>th</sup>			11th			14th			23rd	
Alder Hey <b>SLA</b>					15 <sup>th</sup>			22nd							
Christie <b>SLA</b>								8th							
Leeds Teaching SLA		9th													

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Joint Committee - Performance Management Framework

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			4 Cth			40.1		I	I		<u> </u>	T	I	1
Liverpool Heart and Chest <b>SLA</b>			16 <sup>th</sup>			18th								
Manchester FT SLA									19th					
Robert Jones & Agnus Hunt	22nd													
Royal Liverpool SLA							10th							
Salford <b>SLA</b>	8 <sup>th</sup>													
St Helens & Knowsley <b>SLA</b>				8 <sup>th</sup>										
Sheffield <b>SLA</b>											12th			
Walton Centre SLA			25 <sup>th</sup>			26th								
Cancer & Blood Plastic surgery Performance Management SBUHB	7 <sup>th</sup>	5 <sup>th</sup>	2 <sup>nd</sup>	6 <sup>th</sup>	6 <sup>th</sup>	3 <sup>rd</sup>	1 <sup>st</sup>	5 <sup>th</sup>	3 <sup>rd</sup>	7 <sup>th</sup>	4 <sup>th</sup>	2 <sup>nd</sup>	6 <sup>th</sup>	4 <sup>th</sup>
Cardiac Performance Management C&VUHB	25 <sup>th</sup>		14 <sup>th</sup>											
Mental Health Performance Management	BCUHB 5 <sup>th</sup>				BCUHB 6 <sup>th</sup>			BCUHB 5 <sup>th</sup>			BCUHB 4 <sup>th</sup>			BCUHB 4 <sup>th</sup>
Meetings	SBUHB 6 <sup>th</sup>				SBUHB 7 <sup>th</sup>			SBUHB 6 <sup>th</sup>			SBUHB 5 <sup>th</sup>			SBUHB 5 <sup>th</sup>
Gender Service Performance Management Meetings	16 <sup>th</sup>	7 <sup>th</sup>	4 <sup>th</sup>	1 <sup>st</sup>	1 <sup>st</sup>	5 <sup>th</sup>	3 <sup>rd</sup>	7 <sup>th</sup>	5 <sup>th</sup>	2 <sup>nd</sup>	6 <sup>th</sup>	4 <sup>th</sup>	1st	6 <sup>th</sup>
Neurosurgery	17 <sup>th</sup>		12 <sup>th</sup>		9 <sup>th</sup>		4 <sup>th</sup>		6 <sup>th</sup>		7 <sup>th</sup>			

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Performance											
Management											
Meetings											
Women &	C&VUHB	SBUHB			SBUHB						
Children	7 <sup>th</sup>	20 <sup>th</sup>			27 <sup>th</sup>						
Performance											
Management					C&VUHB 30 <sup>th</sup>						
Services in escalation						•			<u>'</u>	•	
Cancer & Blood			1 <sup>st</sup>								
Burns											
Escalation											
Meeting SBUHB											
Cancer & Blood		5 <sup>th</sup>									
PETIC											
Escalation											
meeting											
Cardiac	25 <sup>th</sup>										
Escalation											
Meeting											
C&VUHB											
Mental Health	9 <sup>th</sup>	13 <sup>th</sup>	10 <sup>th</sup>	14 <sup>th</sup>	14 <sup>th</sup>						
(FACTS)											
Escalation											
Meetings							1	1			

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### **TERMS OF REFERENCE**

TOR Board/Joint Committee
TOR Exec to Exec
TOR Planning Interface Meetings
TOR SLA Meetings
TOR Service Performance Management Framework
TOR Commissioning Teams

3.7 Appendix 1
Joint Committee - Performance Management Framework

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### **BOARD/JOINT COMMITTEE**

The WHSSC Standing Orders can be found here:

https://whssc.nhs.wales/publications/governance/whssc-standing-orders/

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### **EXEC TO EXEC**

**In Development** 

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## PLANNING INTERFACE MEETINGS DRAFT TERMS OF REFERENCE (for consideration)

#### 1. PURPOSE

To ensure strong alignment between the WHSSC Integrated Commissioning Plan and Health Boards Integrated Medium Term Plans, specifically as they relate to the commissioning and provision of Specialist services.

#### Specifically to:

- track progress with implementation of strategic plans (specifically business case development, funding release and performance management)
- share updates on relevant strategic work pieces i.e. Mental Health Specialist Services Strategy, Paediatrics Specialist Services Strategy, Intestinal Failure strategic review.
- Discuss service planning issues, with a view to development or resolution as needed
- Share capital planning developments/issues as they relate to the provision of Specialist Services
- Share information as relevant to the progression of specialist services provision in NHS Wales

#### 2. MEMBERSHIP

Membership of the group will comprise of:

WHSSC	PROVIDER
Director of Planning	Director of Planning
Asst Director of Planning	Asst Director of Planning
Snr Specialised Planners	Planning leads as required
	Corporate Finance lead
	Ops planning lead

Other members can be co-opted to enable depth of agenda items as needed

### 3. QUORACY

The meeting will be deemed quorate when 50% of both organisations are present.

#### 4. FREQUENCY

The meetings will be held quarterly

### 5. BUSINESS MANAGEMENT

Papers for the meeting will be circulated no less than 5 working days in advance of the meeting. This process will be managed by the WHSSC Planning Business Manager

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### **Service Level Agreement Meeting**

### **Terms of Reference**

Version: 0.1 September 2022

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Document information	
Document purpose	Terms of Reference
Author	Director of Planning
<b>Document Lead</b>	Director of Finance
Approved by	
Publication date	TBC
First Review Date	TBC
Second Review Date	TBC
Revision Date	TBC

#### 1. Introduction

The Service Level Agreement (SLA) Meeting Terms of Reference has been established in line with the requirements of the Welsh Health Specialised Services Committee (WHSSC) performance management and assurance framework for the provision of specialised services for the people of Wales.

### 2. Purpose

The purpose of the meeting is to ensure that Health Board/Trust/other service provider services are being delivered in line with contracted activity as outlined within the commissioned SLA.

Providers are required to provide updates and raise issues across the following areas:

### • Awareness of contracted activity across the entire organisation Contract expectations (quality, activity and cost) reiterated each meeting as context for discussion that follows (WHSSC DOF/ADOF)

### Overview of performance (activity, quality and cost)

WHSSC Dashboard – shared monthly by Director of Planning and Performance/Director of Finance

Provider position – Section to include activity against contract, variance and plans to get back on track. Should include both immediate performance plans, and trajectories for recovery

Section also to include any performance issues (under and or over) emerging from WHSSC commissioning meetings and or Service/WHSSC performance management meetings)

### Quality and Patient Safety –

Reminder of quality indicators and expectations within the contract and overview of performance/variance against these

### Areas of service risk/exception

Arising from the service/WHSSC performance management meetings, or anything that has emerged as critical to the sustainability of a service after the meeting or considered corporately

Opportunity to align risk appetite

#### Finance

Receive updates on the 'global' SLA financial position including any reasons for material variance

Deep dive into any areas escalated from service/WHSSC performance management meetings

### Commissioned Services in escalation/impact on contracted activity/plans to get on track

Formal notification (arising from commissioning team and WHSSC/service meeting that a service is being escalated- note will have been agreed at CDGB) Generic updates on services already in escalation beyond that discussed in escalation meetings

Notification of de-escalation

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### Outside of the scope of the SLA meetings are:

- Update against Integrated Commissioning Plan (picked up in planning interface meetings)
- Scrutiny on progress with specific schemes/proposals (Picked up in planning meetings)
- Outcome of horizon scanning/prioritisation (Picked up in planning meetings
- Specific service issues (not needing escalation beyond service/performance level)

### 3. Membership

The meeting will be chaired by:

Director of Finance and Information, WHSSC

In the absence of the Chair the appointed deputy chair is:

Director of Planning and Performance, WHSSC

The SLA meeting membership is presented in Table 1.

Other members may be appointed, or invited to attend specific meetings as deemed appropriate by WHSSC.

**Table 1: SLA Membership list** 

### **WHSSC**

Title	
Director of Finance (Chair)	Stuart Davies
Director of Planning (Deputy Chair)	Nicola Johnson
Assistant Director of Planning	Claire Harding
Assistant Director of Finance	James Leaves
Finance and Contracts Manager	TBC
Specialised Services Planning Manager/s	Various dependent on provider
Information Manager	Sandra Tallon/Dan Lewis/Martin
	Hoff
Quality Lead	Adele Roberts/Vickie Dawson-John

### **Commissioned Provider**

Medical Director	Health Board / Trust
Director of Planning / Performance	Health Board / Trust
Deputy Director of Finance Strategic	Health Board / Trust
Chief Operating Officer (or deputy)	Health Board / Trust
Head of Quality/Quality service lead	Health Board / Trust
Clinical Consultant Lead / Clinical	Health Board / Trust
Representative(s)	

The secretariat function of the group will be provided by the Planning and performance Business Manager/admin officer who will ensure that all papers are distributed at least 5 working days prior to the meeting.

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### 4. Meetings

The Chair will ensure any decisions are balanced, equitable, transparent and unbiased to ensure decisions are made upon the best interests of NHS Wales. The Chair may convene additional meetings as deemed necessary.

The timing of meetings will be arranged to allow adequate time for the business of the meeting to be conducted effectively.

At least 50% of members from both organisations must be present to allow any formal business to take place.

Meetings shall be held on a quarterly basis.

### Dealing with Members' interests during meetings

The Chair will ensure that the decisions on all matters brought before it are taken in an open, balanced, objective and unbiased manner. In turn, individual members need to demonstrate, through their actions, that their contribution to the decision making is based upon the best interests of the NHS in Wales.

Where individual members identify an interest in relation to any aspect of business set out in the meeting agenda, that member should declare the interest at the start of the meeting. Members should seek advice from the Chair if they are in any doubt as to whether they should declare an interest.

All declarations of interest made at a meeting must be recorded in the minutes.

### 5. Reporting and assurance arrangements

The Chair of the meeting shall:

- enable through the secretariat both formal notes, and a generic core brief
- report formally to WHSSC on the meeting activities. This includes the provision of verbal updates, the submission of the action log and written reports
- bring to WHSSC's specific attention any significant or critical matters under consideration

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#### SERVICE PERFORMANCE MANAGEMENT MEETINGS

#### DRAFT TERMS OF REFERENCE (for consideration)

#### **PURPOSE**

To ensure robust performance management arrangements are in place for services commissioned from xxxx service, by WHSSC on behalf of the 7 Health Boards in Wales.

### Specifically:

- WHSSC will develop and issue a performance framework to enable collation of appropriate information relevant to commissioned service
- Provider colleagues will share information against the framework in order to demonstrate performance against commissioned activity
- The group will discuss performance against contracted activity (activity, finance and quality) and will
  provide assurance of delivery, or agree mitigating actions and milestones where there is variance
  beyond the tolerances within the contract
- The group will discuss any service development proposals, in particular those associated with WHSSCs commissioning intentions or related to new and emerging practice, drugs or technology
- The group will identify risks, and issues, escalating as necessary to the broader SLA meeting of the provider and through WHSSC internal processes as required.

#### 6. MEMBERSHIP

Membership of the group will comprise of:

WHSSC	PROVIDER
Senior Specialist Service Planner	Clinical Board/Divisional lead (clinical)
Planning Assistant	Clinical Board/Divisional lead (managerial)
Finance lead	Service lead
Quality lead	Financial support

- Note deputies should be identified to aid quoracy and traction of business
- Other members can be co-opted to enable depth of agenda items as needed

### 7. GOVERNANCE/ORGANISATION



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### 8. QUORACY

The meeting will be deemed quorate when 50% of both organisations are present.

### 9. FREQUENCY

The meetings will be held (Need to check what they are now)

### **10. BUSINESS MANAGEMENT**

Papers for the meeting will be circulated no less than 5 working days in advance of the meeting. This process will be managed by the assistant planner

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#### WHSSC COMMISSIONING TEAM MEETINGS



# Commissioning Team Terms of Reference

# 1.0 Accountability

1.1 The Commissioning Team will be accountable to the Corporate Directors.

# 2.0 Purpose

- 2.1 The Commissioning Team is a multi-professional group that delivers high-quality commissioning advice for the WHSSC Joint Committee.
- 2.2 The Commissioning Teams include the relevant Associate Medical Director, planning, quality, finance and information representatives.
- 2.3 There are five Commissioning Teams (and the Renal Network) which cover all of the services which are delegated by the Health Boards to be commissioned by WHSSC.

# 3.0 Role

The role of the Commissioning Team is:

- To assure the Joint Committee regarding the process of commissioning, and the recommendations made;
- To deliver the commissioning of specialised services on behalf of the Joint Committee
  to ensure a multi-professional approach is taken to the commissioning process,
  providing a structure for co-ordinating the work of the functional departments within
  WHSSC;
- To deliver robust commissioning documentation, particularly Commissioning Policies and Service Specifications;
- To ensure that the commissioning intentions are reflected in the Integrated Commissioning Plan;
- To ensure the commissioning teams work plan fits with the wider priorities of WHSSC and the wider NHS Wales;
- To ensure that quality and risk issues in the commissioned services are formally reported and action taken where appropriate;
- To receive, review and consider appropriate action from the Assistant Director of Evidence and Evaluation.

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# 4.0 Sub Groups and Relationships

- 4.1 The Commissioning Teams will work closely with the Assistant Director of Evidence and Evaluation.
- 4.2 The Specialised Services Planner for the commissioning team will be responsible for ensuring that the development of policies and service specifications is coordinated through the team prior to presentation to the WHSSC Policy Group.
- 4.3 Specific task and finish groups can be established to deliver specified products on behalf of the Commissioning Team.
- 4.4 Timescales for delivery of reports will be in accordance with the agreed timescales as set out in the business cycle for the organisation.
- 4.5 Where appropriate Clinical and Managerial Leads of the relevant Networks will be invited to support discreet pieces of work and attend the Commissioning Teams Meeting

# 5.0 Membership

- 5.1 The Associate Medical Director will chair the meeting.
- 5.2 The core membership of the Commissioning Team will include:
  - Associate Medical Director
  - Specialised Services Planning Manager;
  - Assistant Planning Manager
  - Quality Team Representative;
  - Finance Representative; and
  - Information Representative.
- 5.3 Further individuals, may be co-opted to the Commissioning Team to support specific areas of work.
- 5.4 The Corporate Directors will have an open invitation to attend the Commissioning Team meetings.

# 6.0 Commissioning Team Meetings Administration

# Quorum

6.1 One member from each team should be present to ensure the quorum of the Meeting. Members should provide (where relevant) an update report if unable to attend the meeting.

# Frequency of meetings

6.2 Meetings should be held monthly and no less than 6 weekly.

# **Circulation of Papers**

6.3 The Specialised Planning Manager will ensure that all papers are distributed at least three days prior to the meeting.

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# 7.0 Reporting

#### 7.1 The Chair shall:

- Report formally to the Corporate Directors Group on the Commissioning Team's activities.
- Bring to the Corporate Directors Group attention any significant matters under consideration by the Commissioning Team; and
- Ensure appropriate escalation arrangements are in place to alert the Director of Planning of any urgent or critical matters that may compromise patient care and affect the operation or reputation of the Joint Committee.

# 8.0 Review

These terms of reference shall be reviewed bi-annually by the Corporate Directors Board.

#### 9.0 Addendum

# **Relationships with Networks**

Where appropriate Clinical and Managerial Leads of the relevant Networks will be invited to the Commissioning Teams Meeting.

The individual Commissioning teams will agree whether attendance at the meetings is on a regular basis or on an ad hoc basis to support particular pieces of work.

The Specialist Planner will agree with the Network Clinical and/or Managerial Lead the opportunities for joint initiatives and joint working that maximises the benefits for meeting the needs of patients.

The roles and responsibilities for the Commissioning team and the Network will be agreed and documented at the outset of any joint initiatives.

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# Welsh Health Specialised Services Committee Commissioning Advisory Group (CAG)

**Title:** DRAFT Terms of reference (11<sup>th</sup> July 2017). Version 1.0

**Purpose:** To scrutinise the escalation of quality concerns by the WHSSC team according to the WHSSC Escalation Process:

- To consider whether action plans are reasonable and achievable
- To consider whether there is sufficient mitigation of risk
- To provide advice on the need for further escalation/de-escalation taking into account proportionality and consistency and;
- To provide assurance to the Quality and Patient Safety Committee

#### Membership:

- 4 Health Board (HB) Commissioning Management Representatives. Appointments will be for 2 years and will rotate so that all HBs will have representation on the group over a 4 year period
- 3 patient and public representatives
- WHSSC Director of Nursing and Quality (Chair)
- WHSSC Director of Planning
- WHSSC Quality Manager
- Associate Medical Director and Senior Planner (or deputies) from the relevant Commissioning Team to present evidence and provide further information for the Group

Accountability: To report to the Quality and Patient Safety Committee

#### **Review:**

The group will carry out an annual review its relevance, the value of its work and the terms of reference

# **Working methods:**

- Bi- monthly meetings will be established.
- All services where a stage 3 Commissioning Quality Visit has been carried out or services which have been escalated to stage 4, bypassing stage 3 escalation, will be considered.
- For newly escalated services the group will examine the evidence and provide advice on the appropriateness of the action plan, the mitigation of risk and any further escalation proposed by the WHSSC team
- For previously escalated services the group will examine the ongoing evidence consider whether the requirements of the action plans have been met and advise on the further escalation or de-escalation
- Papers will be circulated 5 working days before the meeting. Confidential papers will be clearly marked.
- The output of the group will be:

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- Advice to the WHSSC team on further evidence which may be required to effectively monitor the service
- A view as to whether the action plan is likely to deliver effective improvement or whether additional requirements should be added or whether requirements should be removed
- o A view as to whether the timelines are appropriate
- o A view as to whether there is sufficient mitigation of existing risk
- A view as whether escalation to stage 3 or 4 was appropriate and whether further escalation is required
- o A summary of their findings for the Quality and Patient Safety Committee

**Quorum:** At least 2 HB members and 2 public and patient representatives should be present.

(SL 12.07.17)

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# **DRAFT AGENDA TEMPLATES**

Agenda -Board/Joint Committee	
Agenda - Exec to Exec	
Agenda - Planning Interface Meetings	
Agenda - SLA Meetings	
Agenda - Service Performance Management Framework	
Agenda - Commissioning Teams	

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#### AGENDA BOARD/JOINT COMMITTEE

Formulated from current strategic issues. Likely to include areas such as:

# For all commissioning organisations:

- Specialised Services Strategy
- Access and Equity for Specialised services for resident population
- Population Health/need
- Value for investment
- Discussion on service developments/risks
- Discussions on how activity further down a pathway may convert to specialised service need (i.e. increased diagnostics, conversion rates etc)
- Any changes to NHSE provision affecting welsh patients
- No surprises

# For specialist service provider organisations:

All of the above, plus issues pertaining to the delivery of services i.e.

- Outsourcing conversations
- Any strategic issues linked to contract performance in particular service areas

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#### **AGENDA EXEC TO EXEC**

Formulated from current strategic issues. Likely to include areas such as:

# For all commissioning organisations:

- Specialised Services Strategy
- Access and Equity for Specialised services for resident population
- Population Health/need
- Value for investment
- Discussion on service developments/risks
- Discussions on how activity further down a pathway may convert to specialised service need (i.e. increased diagnostics, conversion rates etc)
- Any changes to NHSE provision affecting welsh patients
- No surprises

# For specialist service provider organisations:

All of the above, plus issues pertaining to the delivery of services ie

- Outsourcing conversations
- Any strategic issues linked to contract performance in particular service areas

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# **AGENDA PLANNING INTERFACE MEETINGS**



# PLANNING INTERFACE MEETING WHSSC and XXXX Health Board

_		Lead	Att.
1	Welcome and introductions		
2	Notes/actions from previous meeting		
3	Overview of Business Case position		
	o Previous ICP year		
	BC's outstanding		
	o Current ICP year		
	Business Cases received		
	Business Cases outstanding		
	o Forthcoming ICP		
	Schemes prioritised for investment		
5	Strategic planning issues		
	Paediatric strategy		
	<ul> <li>Mental Health strategy</li> </ul>		
	o Intestinal Failure Strategic review		
4	Service planning issues		
	Eg Paediatric Neurology, paediatric pathology		
5	Capital planning issues		
6	General Information exchange		
7	Any Other Business		

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# **AGENDA SLA MEETINGS**



# **SERVICE LEVEL AGREEMENT MEETING**

# **BETWEEN WHSSC AND XXXXXXX HEALTH BOARD**

No.	Item	Lead	Att.
1	Welcome & Introductions	Chair	
2	Summary of Contract (value, activity levels etc)	DOF	
3	<ul> <li>Performance against contracted volumes (Activity)</li> <li>WHSSC data pack/dashboard</li> <li>Provider perspective</li> </ul>	NJ TBC	
4	<ul> <li>Performance against contract – Quality</li> <li>Quality indicators within contract</li> <li>Performance/variance</li> <li>Any service quality issues as escalated through WHSS/service discussions</li> </ul>		
5	Performance against contract – finance		
6	<ul> <li>Escalation</li> <li>Services in formal escalation arrangements</li> <li>Any issues of escalation from WHSSC/Service meetings</li> </ul>		
7	Any Other Business		

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# **STANDARDISED AGENDA (ALIGNS WITH STEEP)**

<u>1</u>	Welcome
<u>2</u> <u>3</u>	Notes and actions from previous meeting
<u>3</u>	Update against investment
	<ul> <li>Staff structure</li> <li>Benchmark against investment profile/service specification</li> </ul>
4	Activity
	<ul> <li>Waiting list position</li> <li>Outreach waiting list</li> <li>Diagnostics</li> </ul>
<u>5</u>	Key Performance Indicators for the service
<u>6</u>	Quality update
	<ul> <li>Staffing (wellbeing)</li> <li>Incident reporting / lessons learnt</li> <li>Patient Experience (concerns / PREMS / Patient stories)</li> <li>PROMS</li> </ul>
<u>7</u>	Risk
<u>8</u>	Any areas requiring escalation to SLA meeting
<u>9</u>	Any other business

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# **COMMISSIONING TEAM AGENDA**



Pwyllgor Gwasanaethau lechyd Arbenigol Cymru (PGIAC)

Welsh Health Specialised
Services Committee (WHSSC)

# Agenda XXXXXXXXX Commissioning Team Meeting

AGEN	DA ITEM	Lead	Att.
1.1	Apologies for Absence		
1.2	Action notes from the last meeting – 23rd August 2022		
1.3	Closed Action Log		
2. P	erformance / Information / Finance		
2.1	Monthly BI Performance Report including all services – Activity, KPI's and Waiting times		
2.2	Monthly Finance Report Finance Report – All Welsh Health Boards, NHS E providers		
2.3	North Wales issues		
	uality & Patient Safety		
3.1	<ul> <li>Risk Register</li> <li>Serious Incidents – Outcome and Action Plans</li> <li>Service Improvement Days</li> </ul>		
4. W	ork plan		
4.1	<ul><li>ICP 2022-25</li><li>Business cases in</li><li>Business cases awaited</li></ul>		
4.2	<ul><li>ICP 2023-26</li><li>CIAG Schemes – to be taken forward</li></ul>		
5. P	plicies and Service Specifications		
	Policies in Development Policies on Work plan	LK	Att.7
6.	Issues for escalation/external discussion		
	<ul><li>Next WHSSC service interface meeting</li><li>SLA meeting</li></ul>		
7.	Any Other Business		
8.	Date of Next Meeting		

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# WHSSC ESCALATION PROCESS

The WHSSC escalation process can be found here: <a href="https://whssc.nhs.wales/publications/corporate-policies-and-procedures/corp-24c-escalation-process/">https://whssc.nhs.wales/publications/corporate-policies-and-procedures/corp-24c-escalation-process/</a>

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Report Title	-	of the Integra ng Plan 2024 -	Agenda Item	3.8				
Meeting Title	Joint Commit			<b>Meeting Date</b>	16/05/2023			
FOI Status	Open							
Author (Job title)	Assistant Direc	tor of Planning						
Executive Lead (Job title)	Director of Plar	nning						
Purpose of the Report	The purpose of this report is to outline the high level process for the development of the WHSSC Integrated Commissioning Plan (ICP) for 2024-2027.							
Specific Action Required	RATIFY	APPROVE	SUPPORT	ASSURE	INFORM			

Members are asked to:

- Note the report,
  Consider and approve the timeline; and
- Receive assurance on the process.

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# DEVELOPMENT OF THE INTEGRATED COMMISSIONING PLAN (ICP) 2024 - 2027

# 1.0 SITUATION

The purpose of this report is to outline the high level process for the development of the WHSSC Integrated Commissioning Plan (ICP) for 2024-2027.

#### 2.0 BACKGROUND

Each year WHSSC develops an ICP on behalf of the seven Health Boards (HBs) in Wales, and in response to the Welsh Government (WG) Planning Guidance.

# 3.0 ASSESSMENT

An indicative development plan and timeline for the production of the 2024-2027 ICP has been developed and is presented at **Appendix 1** for information.

The context within which the ICP is being developed this year, means that there will be additional emphasis on recommissioning and redesign. As such, additional steps have been added to the process to reflect this – i.e. the introduction of a recommissioning and efficiency Board, and a workshop on benchmarking, reviews and best practice.

### 4.0 RECOMMENDATIONS

Members are asked to:

- Note the report,
- Consider and approve the timeline; and
- Receive assurance on the process.

Governance and Assura	ince
Link to Strategic Object	tives
Strategic Objective(s)	Governance and Assurance Development of the Plan Choose an item.
Link to Integrated Commissioning Plan	This process outlines how the ICP for 24/27 will be developed
Health and Care Standards	Governance, Leadership and Accountability Choose an item. Choose an item.
Principles of Prudent Healthcare	Reduce inappropriate variation Care for Those with the greatest health need first Only do what is needed
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 The health and social care workforce is motivated and sustainable Wales has a higher value health and social care system that has demonstrated rapid improvement and innovation, enabled by data and focused on outcome Choose an item.
<b>Organisational Implicat</b>	tions
Quality, Safety & Patient Experience	Issues of Quality, Safety and Patient experience are integral to the development and implementation of the ICP
Finance/Resource Implications	The plan will have resource implications both staffing and financial
Population Health	The plan is driven by the population health needs of the Welsh population
Legal Implications (including equality & diversity, socio economic duty etc.)	The plan is developed with cognisance to the requirements of varying legislative requirements, including those associated with equality & diversity, socio economic duty etc.
Long Term Implications (incl. WBFG Act 2015)	The plan is developed with issues of long term sustainability and future generations in mind.
Report History (Meeting/Date/ Summary of Outcome	-
Appendices	Appendix 1 – Timeline for the Development of the Integrated Commissioning Plan (ICP) 2024-2027.

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# **Integrated Commissioning Plan Process 2024-2027**

	Dec 22	Jan 23	Feb 23	Mar 23	Apr 23	May 23	Jun 23	Jul 23	Aug 23	Sep 23	Oct 23	Nov 23	Dec 23	Jan 24
Plan Submission date to Welsh Government				X										
Reflections Workshop/exercise				X	Х									
Health Board Engagement Sessions					Х	Х								
Development of commissioning intentions					Х	Х								
Re-commissioning, Benchmarking, Best practice workshop							Х							
Commissioning intentions cascaded							Х							
CIAG submissions								X						
CIAG scrutiny /sift								X						
CDGB share of schemes and sift outcome								X						
Disseminate final CIAG Pack								X						
Horizon scanning and prioritisation process								x						
CIAG Day									X					
Consider Progress on Delivery of ICP 2022/23 at Q2 and assess commissioning risks										X				
Outcome of CIAG to Management Group Paper to be submitted by 9th Sept										Х				
<b>Draft ICP to Management Group</b> Paper to be submitted by 10 <sup>th</sup>											х			
<b>Draft ICP to Joint Committee</b> Paper to be submitted by 31st Oct												x		
Allocation letter to be received and Final ICP to be approved at Joint Committee Paper to be submitted by 2 <sup>nd</sup> Dec													X	
Plan Submission to WG													x	

Report Title	Annual Governance Statement 2022-2023	Agenda Item	3.9				
<b>Meeting Title</b>	Joint Committee	<b>Meeting Date</b>	16/05/2023				
FOI Status	Open						
Author (Job title)	Head of Corporate Governance						
Executive Lead (Job title)	Committee Secretary & Associate Director of Governance						
Purpose of the Report	The purpose of this report is present the Annual Governance Statement (AGS) 2022-23 for approval.						
Specific Action Required	RATIFY APPROVE SUPPO	ORT ASSURE	INFORM				

# Recommendation(s)

Members are asked to:

- Note the final report,
- **Note** that the draft Annual governance Statement was presented to the Integrated Governance Committee on the 18 May 2023 for assurance,
- **Note** that the WHSSC Annual governance Statement 2022-2023 will be presented at the CTMUHB Audit & Risk Committee Meeting on 21 June 2023,
- **Note** that the WHSSC Annual Governance Statement 2022-2023 will be included in the CTMUHB Annual report submission to Welsh Government and Audit Wales in June 2023, recognising that it has been reviewed and agreed by the relevant sub committees of the Joint Committee;
- Note that the final documents will be submitted to the CTMUHB Audit & Risk Committee in July 2023 for recommendation for CTMUHB Board Approval on 27 July 2023; and
- **Note** that the final Annual Governance Statement will be included in the Annual Report presented at the CTMUHB Annual General Meeting in September 2023.

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# **ANNUAL GOVERNANCE STATEMENT 2022-2023**

# 1.0 SITUATION

The purpose of this report is present the Annual Governance Statement (AGS) 2022-23 for approval.

#### 2.0 BACKGROUND

Chapter 3 of the HM Treasury 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 (including an Annual Governance Statement (AGS)) and Financial Statements.

As a hosted body under Cwm Taf Morgannwg UHB (CTMUHB), WHSSC does not have a statutory duty to produce an AGS and an Annual report but does so, as a matter of good governance in accordance with section 9.0.2 of the WHSSC Standing Order's (SO's), to provide assurance to the LHBs and, in particular, to CTMUHB, as its host organisation, in relation to its governance and accountability arrangements.

The AGS is a key feature of an organisation's Annual Report and Accounts and demonstrates publicly the management and control of resources and the extent to which the body complies with its own governance requirements, including how they have monitored and evaluated the effectiveness of their governance arrangements. It is intended to bring together in one place all disclosures relating to governance, risk and control.

This report requests that the Joint Committee approve the AGS 2022-2023.

A separate Annual Report reflecting on WHSSC's performance and its achievements over the last financial year and reflecting on what was achieved in collaboration with partner organisations and stakeholders is being developed and will be presented to the IGC on 13 June 2023, prior to being submitted to the Joint Committee meeting on 18 July 2023 for final approval in accordance with the scheme of delegation.

#### 3.0 ASSESSMENT

#### 3.1 Annual Governance Statement 2023-2023

The AGS covering the period 1 April 2022- 31 March 2023 is presented at Appendix 1. The document and provides a clear understanding of WHSSC as an organisation and its' internal control structure, the stewardship of the

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organisation, an explanation of the risks the organisation is exposed to both currently and looking forward – and how these are mitigated, the potential impact of the risks and operating environment on the achievements of the organisation, and how the organisation has coped with the challenges faced.

# 3.2 Timelines

The timelines for submitting the required information to CTMUHB is outlined below:

Date	Task
18 April 2023	Draft AGS presented to IGC for review.
20 April 2023	Draft AGS presented to CDGB
16 May 2023	Final WHSSC AGS presented to the Joint
	Committee for approval.
13 June 2023	Final WHSSC AGS to be presented to the IGC
	for information.
21 June 2023	WHSSC AGS 2022-2023 to be presented to
	CTMUHB ARC.
	FINAL version of WHSSC AGS and annual
	accounts will be included as part of the
	CTMUHB Annual Report submission to Welsh
	Government & Audit Wales.
July 2023	Final documents will be submitted to the
	CTMUHB Audit & Risk Committee in July 2023
	for recommendation for CTMUHB Board
	Approval on 27 July 2023
September	CTMUHB Annual General Meeting (AGM)
2023	

The AGS has been assembled from work through the year to gain assurance about performance and insight into the organisation's risk profile, its responses to the identified and emerging risks and its success in tackling them.

# 4.0 RECOMMENDATIONS

Members are asked to:

- **Note** the report,
- **Note** that the draft Annual governance Statement was presented to the Integrated Governance Committee on the 18 May 2023 for assurance,
- Note that the WHSSC Annual governance Statement 2022-2023 will be presented at the CTMUHB Audit & Risk Committee Meeting on 21 June 2023,
- **Note** that the WHSSC Annual Governance Statement 2022-2023 will be included in the CTMUHB Annual report submission to Welsh Government and Audit Wales in June 2023, recognising that it has been reviewed and agreed by the relevant sub committees of the Joint Committee,
- Note that the final documents will be submitted to the CTMUHB Audit & Risk Committee in July 2023 for recommendation for CTMUHB Board Approval on 27<sup>th</sup> July 2023; and
- **Note** that the final Annual Governance Statement will be included in the Annual Report presented at the CTMUHB Annual General Meeting in September 2023.

<b>Governance and Assu</b>	rance					
Link to Strategic Obje						
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 Implic	cations					
Quality, Safety & Patient Experience	Governance: to be a well-governed organisation with high standards of assurance, responsive to members and stakeholders in transforming services to improve patient outcomes.					
Finance/Resource Implications	There were no impacts identified in this area.					
Population Health	Not applicable					
Legal Implications (including equality & diversity, socio economic duty etc.)	There may be an adverse effect on the organisation if there are no arrangements to publish the Annual Governance Statement.					
Long Term Implications (incl. WBFG Act 2015)	Not applicable					
Report History (Meeting/Date/ Summary of Outcome	18 April 2023 – IGC – discussed and endorsed 21 April 2023 – CDGB – discussed and endorsed					
Appendices	Appendix 1 – Annual Governance Statement 2022-2023.					



# **Annual Governance Statement 2022-2023**

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# ANNUAL GOVERNANCE STATEMENT 2022-2023

# 1.0 SCOPE OF RESPONSIBILITY

In accordance with the Welsh Health Specialised Services Committee (Wales) Directions 2009 (2009/35) and 2014 (2014/9 (w.9)) (the Directions), the Local Health Boards (LHBs) established a joint committee known as the Welsh Health Specialised Services Committee (the Joint Committee or WHSSC), which commenced on 1 April 2010, for the purpose of jointly exercising its Delegated Functions and providing the Relevant Services.

In establishing WHSSC to work on their behalf, the seven LHBs recognised that the most efficient and effective way of planning the Relevant Services was to work together to reduce duplication and ensure consistency.

WHSSC's aim is to ensure that there is:

"Equitable access to safe, effective and sustainable specialist services for the people of Wales, as close to patients' homes as possible, within available resources"

In order to achieve this aim, WHSSC works closely with each of the Local Health Boards (LHBs) (in both their commissioner and provider roles) as well as with Welsh NHS Trusts, providers in NHS England and the independent sector.

The commissioning of specialised services is informed through the application of the Prudent Healthcare Principles and the 'Quadruple Aim' identified in the Parliamentary Review of Health and Social Care in Wales, published in 2018.

WHSSC is committed to supporting achievement of the objectives outlined in <u>A healthier Wales</u> to ensure that people stay healthy for as long as possible, and to supporting achievement of the ambitious objectives outlined in Welsh Government's <u>"Health and Social Care in Wales COVID-19: Looking Forward"</u> guidance and adopt a realistic approach to supporting building back our health and care system in Wales, in a way that places fairness and equity at its heart.

The Welsh Health Specialised Services Committee (Wales) Regulations 2009 (SI 2009 No 3097) (the Regulations) make provision for the constitution of the Joint Committee including its procedures and administrative arrangements.

The Joint Committee is a statutory committee established under sections 12 (1) (b) and (3), 13(2) (c), (3) (c) and (4) (c) and 203(9) and (10) of the National Health Service (Wales) Act 2006. The LHBs are required to jointly exercise the Relevant Services.

V-0.11 Page 3 of 55 WHSSC Annual Governance Statement 2022-2023 Cwm Taf Morgannwg University Health Board (CTMUHB) is the identified host organisation. It provides administrative support for the running of WHSSC and has established the Welsh Health Specialised Services Team (WHSST) as per Direction 3(4), Regulation 3(1) (d) and the interpretation sections of both the Directions and the Regulations and the Joint Committee Standing Orders: Statutory Framework and Joint Committee Framework.

The Joint Committee is accountable for Governance, Risk Management and Internal Control. As Managing Director for Specialised and Tertiary Services Commissioning, NHS Wales, I have responsibility for maintaining appropriate governance structures and procedures as well as a sound system of internal control that supports the achievement of the Joint Committee's policies, aims and objectives whilst safeguarding the public funds and the organisation's assets for which I am personally responsible; and to report the adequacy of these arrangements to the Chief Executive of CTMUHB in accordance with the responsibilities assigned by the Accountable Officer of NHS Wales. Under the terms of the establishment arrangements, CTMUHB is deemed to be held harmless and have no additional financial liabilities beyond its own population.

WHSSC does not have a statutory duty to produce an Annual Governance Statement (AGS) but does so, as a matter of good governance, to provide assurance to the LHBs and, in particular, to CTMUHB, as its host organisation, in relation to its governance and accountability arrangements.

This report outlines the different ways the organisation has had to work both internally and with partners in response to the unprecedented pressure in planning and providing services. It explains arrangements for ensuring standards of governance are maintained, risks are identified and mitigated and that assurance has been sought and provided.

#### 2.0 OUR GOVERNANCE FRAMEWORK

In accordance with the WHSSC Regulations 2009, each Local Health Board (LHB) in Wales must agree Standing Orders (SOs) for the regulation of the Joint Committee proceedings and business. These Joint Committee standing orders form a schedule to each LHB's own standing orders, and have effect as if incorporated within them. Together with the adoption of the Scheme of Decisions Reserved to the Joint Committee; the Scheme of Delegations to Officers and Others; and the Standing Financial Instructions (SFIs), they provide the regulatory framework for the business conduct of the Joint Committee.

These documents, together with the Memorandum of Agreement setting out the governance arrangements for the seven LHBs and a Hosting Agreement between the Joint Committee and Cwm Taf Morgannwg University Health Board (as the

Host LHB), form the basis upon which the Joint Committee's Governance and Accountability Framework is developed.

Updated Model Standing Orders and Model Standing Financial Instructions were issued by the Minister for Health and Social Services in correspondence received on the 7 April 2021. Revised Governance and Accountability Framework documents, including the SOs and SFIs, for WHSCC were approved by the Joint Committee on 13 July 2021, and were subsequently taken forward for approval by the seven LHBs for inclusion as schedule 4.1 within their respective LHB SOs.

To ensure effective governance and to comply with the provisions of the WHSSC Standing Orders (SOs) it is important that the SOs and Standing Financial Instructions (SFIs) are kept up to date to comply with the need for:

- The Joint Committee to take appropriate action to assure itself that all matters delegated are effectively carried out, and that
- The framework of delegation is kept under active review and, where appropriate, is revised to take account of organisational developments, review findings or other changes.

The governance and accountability framework was updated in 2022-2023 and approved by the Joint Committee on 14 March 2023. The updated documents were issued to the seven HBs for approval and inclusion as schedule 4.1 within their respective HB SOs. The changes included:

# Financial Limits and Reporting

On <u>10 January 2023</u> the Joint Committee approved that the increased financial delegation limits, introduced in March 2020 to enable effective financial governance as a consequence of the COVID-19 pandemic, could be adopted as new permanent limits. In addition, they approved the updated process for the current SFI requirement for Joint Committee "approval" of non-contract cases above defined limits for annual and anticipated lifetime cost, to be replaced by an assurance report to Joint Committee and the CTMUHB Audit & Risk Committee (ARC). This report will notify the Committees of all approvals above the defined limit and the Chairs action required to meet the need for timely approval.

# Updated Governance and Accountability Framework

Updated SOs, MoA, Hosting Agreement and SFIs were approved by the Joint Committee on <u>14 March 2023</u>. The changes incorporated the above permanent financial limits. The only other changes related to bespoke elements required for WHSSC as summarised below.

# Memorandum of Agreement – Designation of Audit & Finance Lead Independent Member (IM)

On <u>18 January 2022</u>, the Joint Committee approved that the existing arrangements for appointing a CTM audit lead IM, could transition to advertising for an Audit/Finance IM through a fair and open selection process through advertising the vacancy through the HB Chairs and the Board Secretaries, with

eligibility confined to existing HB IMs. Section 7.3 of the MoA has been updated to reflect this.

# Welsh Kidney Network (WKN)

Further to the recent governance review undertaken on the Welsh Kidney Network (WKN) to evaluate and determine the adequacy of the systems and controls in place within WHSSC, the scheme of delegation was updated.

- Delegated authority for the network board including which matters are reserved to itself to include executive officer responsibilities and financial delegation limits; and
- Delegated financial limits within the Standing Financial Instructions.

A copy of the 2023 WHSSC Joint Committee Governance and Accountability Framework is available at:

https://whssc.nhs.wales/publications/governance

#### 2.1 The Joint Committee

The Joint Committee was established in accordance with the Directions and Regulations to enable the seven LHBs in NHS Wales to make collective decisions on the review, planning, procurement and performance monitoring of agreed specialised and tertiary services (Relevant Services) and in accordance with their defined delegated functions.

Whilst the Joint Committee acts on behalf of the seven LHBs in undertaking its functions, the responsibility of individual LHBs for their residents remains. They are therefore accountable to citizens and other stakeholders for the provision of specialised and tertiary services.

The membership of the Joint Committee consists of 15 voting members and 3 Associate members. The voting members include the Chair (appointed by the Minister for Health and Social Services), the Vice Chair (appointed by the Joint Committee from existing non-officer members of the seven LHBs), two other non-officer members (appointed by the Joint Committee from existing non-officer members of the seven LHBs), the LHB Chief Executives and WHSSC Officers.

Decisions taken at Joint Committee meetings are subject to a two-thirds majority of voting members present. Deputies, who must be LHB Executive Directors, may be nominated by LHB Chief Executives; they formally count towards the quorum and have voting rights.

The Joint Committee is supported by the Committee Secretary, who acts as the guardian of good governance within the Joint Committee. Committee Secretary, Jacqueline Evans, started at WHSSC on 1 June 2021.

# 2.1.1 Independent Member (IM) Remuneration

The Audit Wales review into the Committee Governance arrangements at WHSSC report included the need to recognise the complexity of the IM role within WHSSC and the consideration of remuneration. In response to this WHSSC began discussions with Welsh Government on the potential to remunerate WHSSC IM's.

The JC approved a proposal to remunerate WHSSC IMs from 1 April 2022 at its meeting on 18 January 2022. They also agreed a transition to a fair and open selection process for appointing WHSSC IMs through advertising the vacancies through the HB Chairs and the Board Secretaries, with eligibility confined to existing HB IMs.

The Joint Committee papers and confirmed minutes can be viewed on the link below:

https://whssc.nhs.wales/joint-committee/committee-meetings-and-papers/

# 2.1.2 Appointments

As at 1 April 2022, the WHSSC Independent Members consisted of Professor Ian Wells from CTMUHB (Audit/Finance Lead IM) and Professor Ceri Phillip from C&VUHB (Chair of WHSSC QPSC). Following Ian Philips appointment as the substantive Chair for the Welsh Renal Clinical Network (WRCN), with effect from the 1 April 2022, this left the generic IM and Vice Chair position vacant.

A recruitment exercise commenced in August 2022 to appoint two new WHSSC IMs (generic WHSSC IM and an Audit/Finance Lead IM) in accordance with the IM appointment process agreed by the Joint Committee on 18 January 2022. The vacancies were advertised through the HB Chairs and the Board Secretaries, with eligibility confined to existing HB IMs.

Chantal Patel, HDdUHB, was appointed as the new WHSSC IM (Generalist) and Steve Spill, SBUHB, was appointed as the new WHSSC IM (Finance and Audit). Both roles were appointed for a 2-year period with effect from 30 November 2022.

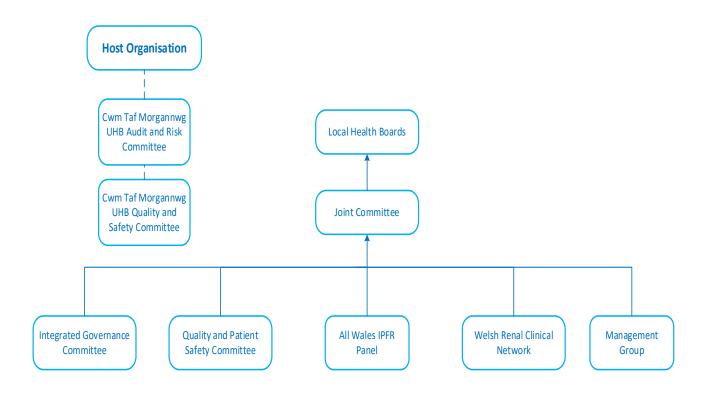
Professor Ian Wells' tenure as an Independent Member ceased on 30 November 2022.

A recruitment process for the third WHSSC IM position will open in April 2023.

# 2.2 Joint Sub-Committees and Advisory Groups

In accordance with WHSSC Standing Order 3, the Joint Committee, where directed by the LHBs jointly or the Welsh Ministers, must appoint joint subcommittees of the Joint Committee either to undertake specific functions on the Joint Committee's behalf or to provide advice and assurance to others (whether directly to the Joint Committee, or on behalf of the Joint Committee to each LHB Board and/or its other committees).

The Joint Committee governance structure is outlined below:



# 2.2.1 Sub-Committees

The Joint Committee has established <u>five joint sub-committees</u> in the discharge of its functions:

- All Wales Individual Patient Funding Request (IPFR) Panel (WHSSC),
- Integrated Governance Committee (IGC),
- Management Group (MG),
- Quality & Patient Safety Committee (QPSC); and
- Welsh Kidney Network (WKN)

The All Wales Individual Patient Funding Request (IPFR) Panel (WHSSC) is constituted to act as a Sub Committee of the Joint Committee, 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 terms of reference for the panel are outlined in the "All NHS Wales Policy Making Decisions on Individual Patient Funding Requests (IPFR)".

The All Wales IPFR Panel meetings were stood down between January – May 2022 in response to the system pressures related to the current wave of the pandemic and the letter from Judith Paget, CEO of NHS Wales regarding use of the Options Framework and the necessity to step down non-essential activities. The Chair's Action Panel continued to operate up until May 2022. IPFR requests were dealt

with virtually and a Chair's Action panel process, (strengthened by including the attendance of two WHSSC Clinical Directors and a lay member representative) were undertaken on an almost weekly basis. From 23 May 2023, full All Wales IPFR Panel meetings were resumed with meetings being held twice monthly. After reinstating the full IPFR meetings, a total of three meetings were stood down due to the panel not being able to achieve quoracy. All other meetings were held as full IPFR Panel Meetings.

There continued to be longstanding issues and risks which pre-dated, but were exacerbated by, the COVID-19 pandemic related to the terms of reference (ToR) of the All Wales IPFR Panel.

In November 2020, discussions commenced to amend the ToR of the All Wales IPFR Panel to address longstanding issues of quoracy and to address the challenges arising from the COVID-19 pandemic.

The JC were unable to approve the updated ToR in <u>November 2020</u> and the practical implications of not being able to update them was that the WHSSC IPFR panel was often non-quorate, or lacked the presence of a chair due to diary commitments. Given that the Panel was frequently subject to challenge (including Judicial Review) this represented a significant risk to WHSSC and has remained as a high risk on the corporate risk register.

A further report was submitted to the Joint Committee on <u>9 November 2021</u> indicating that clarification regarding the appropriate governance route for changes to the ToR had not yet been received from Welsh Government and to alert the Committee of the risks related to this.

Following this, on the 3 December 2021 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 cytoreductive surgery with hyper thermic intraperitoneal chemotherapy (CRS with HIPEC) to treat MW's colorectal cancer, was quashed by the court.

The application for funding for the intervention recommended by her clinician was reconsidered "afresh" by the WHSSC IPFR panel on 16 December 2021.

The judgment handed down on 3 December 2021 focussed on three key areas:

- The All NHS Wales Policy Making Decisions on Individual Patient Funding Requests (IPFR),
- The definition of the comparator group,
- The record of the Panel's reasoning.

Updates on progress were provided to the Joint Committee on <u>18 January 2022</u> and <u>15 March 2022</u>. On 28 July 2022, Welsh Government (WG) wrote to WHSSC and advised that a process of engagement for a specific and limited review of the All Wales IPFR policy wording and changes to the WHSSC IPFR Panel ToR should

be undertaken. Following the engagement process, the amended Policy and new TORs, should be submitted to the Joint Committee for consideration, and then go to HBs for final approval in keeping with the previous approaches taken by WHSSC when making complex or contentious decisions and in keeping with the WHSSC Standing Orders (SOs).

WG also advised that any changes should be submitted to the Joint Committee for consideration and then go back to HBs for final approval. Any changes agreed with HBs should then be shared with WG. In addition, they advised that they fully supported a move to appoint a remunerated chair for WHSSC's IPFR panel and were agreeable to further discussions on this.

On the <u>6 September 2022</u>, the Joint Committee (JC) approved the proposal for WHSSC to undertake an engagement process with key stakeholders to update the WHSSC IPFR Panel ToR and on the specific and limited review of the All Wales IPFR Policy. It was agreed the process should include the All Wales Therapeutics and Toxicology Centre (AWTTC), the IPFR Quality Assurance Advisory Group (AWTTC QAG), the Medical Directors and the Board Secretaries of each of the HB and Velindre University NHS Trust (VUNT). On <u>8 November 2022</u>, the Joint Committee approved the methodology for engagement allowing WHSSC to start the process.

On <u>14 March 2023</u> the updated WHSSC ToR were approved by the Joint Committee and the feedback from the engagement process on the All Wales IPFR Policy was presented. The tenure of the interim Chair of the IPFR Panel was also extended by the Joint Committee to 30 September 2023 to ensure business continuity.

IPFR governance was identified as a risk on the WHSSC Corporate Risk and Assurance Framework (CRAF) on 20 October 2021 and was escalated from 16 to 20 following the judgment handed down in the Judicial Review case in December 2021. The risk score has remained at 20 since and will be reviewed once the review of the all Wales IPFR Policy is concluded and the new ToR are implemented. It is anticipated that this will happen during the summer of 2023.

The **Integrated Governance Committee (IGC)** scrutinises evidence and information brought before it in relation to activities and potential risks that impact on the services provided and provides assurance to the Joint Committee that effective governance and scrutiny arrangements are in place across the organisation. For example, the IGC plays a key role in developing the approach for the annual Committee Effectiveness exercise and oversees the Declaration of Interest process.

During 2022-2023, the IGC continued to monitor and track progress against the recommendations outlined in the Audit Wales report on Committee governance arrangements at WHSSC, on behalf of the Joint Committee.

They IGC received regular updates on the revised Corporate Risk and Assurance Framework (CRAF), which was developed during the past 12 months, and they provided scrutiny of the CRAF before it was presented to the Joint Committee for approval, the WHSSC Quality & Patient Safety Committee and the CTMUHB Audit & Risk Committee (ARC) for assurance. The IGC also received quarterly updates on the Delivery of the Integrated Commissioning Plan throughout 2022-2023.

The Welsh Kidney Network (WKN) Governance Plan was presented to the IGC at its February 2023 meeting. The monitoring of this action plan will be a key focus for the IGC in 2023.

The **Management Group (MG)** is the specialised services commissioning operational body responsible for the implementation of the Specialised Services Strategy. The group underpins the commissioning of specialised services to ensure equitable access to safe, effective, sustainable and acceptable services for the people of Wales.

An induction session for new members was held on 23 June 2022.

During 2022-2023, the Group held a series of workshops focused on evaluation of specific specialised services. This included a Plastic Surgery Commissioning Arrangements Workshop which was held on 22 September 2022 and a review of specialist Haematology services in January 2023. The Haematology workshop was held and supported by Professor Chris Fegan, Consultant Haematologist, CVUHB who had been commissioned by WHSSC to undertake the Haematology review. From the workshop a suite of papers were developed and taken through Management Group and Health Boards. The final proposals linked to the outputs from this workshop will be submitted to the May 2023 Joint Committee meeting for final approval to ensure the future development of Haematology services in Wales.

In addition to these workshops, MG received presentations on Major Trauma, Congenital Heart Disease, and a Single Commissioner Model for Mental Health and a Paediatric Services Deep Dive.

To support the Integrated Commissioning Process for 2023-2024 an overview of the Schemes received by the Clinical Impact Assessment Group (CIAG) was provided during the July 2022 meeting. In November 2022, a recommissioning For Value Workshop took place following a request from JC to review prioritised schemes and to obtain feedback from MG members.

The workshop was planned in response to the Joint Committee's request for scenarios to make choices on commissioning plans and prioritised schemes. The workshop also provided the opportunity to discuss the approach to becoming a more strategic commissioner and to Value-based commissioning.

An updated ICP with a range of financial scenarios was presented to MG in December 2022 and following discussion at the <u>January 2023</u> JC meeting, a

workshop to finalise the details of the ICP took place with MG members on 26 January 2023. A financial summary with a composite scenario was presented in response to the discussion at JC on 17 January 2023. This workshop was helpful and enabled WHSSC to present a final ICP Plan for approval to the JC on  $\underline{13}$  February  $\underline{2023}$ .

As a condition of signing off the Integrated Commissioning Plan, WHSSC and Health Board staff are requested to make a 1% pathway saving (approximately £7m). An efficiency and recommissioning workshop was held on  $23^{rd}$  March, which set out the programme approach for the work as well as seeking to generate proposals for containment within the programme.

The **Quality & Patient Safety Committee (QPSC)** provides assurance to the Joint Committee in relation to the arrangements for safeguarding and improving the quality and safety of specialised services within the remit of the Joint Committee.

The quality of care and experience that patients and their families receive is central to the commissioning of specialised services. Quality is everyone's business and all of our staff strive to ensure that quality and patient centred services are at the heart of commissioning.

An overarching goal of WHSSC is to improve outcomes for people, whoever they are and wherever they live, by providing them with access to high-quality specialised services. To achieve this aspiration of having a quality-led commissioned service, we need to operate within an effective quality management system. The WHSSC Quality Framework first developed in July 2014 was re-launched as the Commissioning Assurance Framework (CAF), and was endorsed by the WHSSC Quality & Patient Safety Committee on 10 August 2021 and approved by the Joint Committee on the <u>7 September 2021</u>. This 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.

During 2022-2023, a successful development day took place on 26 February 2022. The development day provided demonstrations on Data Systems such as QSIS, Once for Wales and MAIR. A key focus of the development day was the updated Escalation Trajectory.

In order to implement the Quality Framework (2015) a quality team was appointed in 2019 to strengthen the focus on quality monitoring and improvement. The 'Quality Team' have a pivotal role in the co-ordination of quality monitoring and interventions within commissioned services. In addition, there is a focus on building relationships with providers to develop robust reporting mechanisms. Internally, they work closely with the Medical Directorate, within the Commissioning Teams in order to monitor the quality elements of commissioned services.

A key element of commissioning serves is ensuring that patients are put at the centre and is seen pivotal to the success of the framework. Patient experience is an important element of the quality cycle capturing both patient experience and concerns raised whilst accessing specialised services.

The **Welsh Kidney Network (WKN)** (previously known as the **Welsh Clinical Renal Network (WRCN)**) is a vehicle through which specialised renal services are planned and developed on an all Wales basis in an efficient, economical and integrated manner and provides a single decision-making framework with a clear remit, responsibility and accountability.

In March 2022, the WKN held a workshop to consider developing and strengthening the work of the network. Some issues were identified regarding the complexity of the current governance arrangements and it was recognised that since 2011 there had been significant changes to the governance environment within the NHS in Wales and that a review of the governance of the network had never been undertaken. It was suggested that a bespoke piece of work be undertaken to describe the issues and associated risks and if necessary make recommendations as to how these might be addressed.

A governance review was undertaken by Steven Combe, Independent Governance Advisor, as a way of identifying any potential governance issues that the WKN needed to address the governance review was undertaken over the summer 2022 and an Action Plan was developed and approved by the WKN Board on 6 October 2022.

The overall objective of the review was to evaluate and determine the adequacy of the systems and controls in place within the Welsh Health Services Specialist Committee (WHSSC) in relation to the WKN.

The review aimed to provide assurance to the Managing Director that the network is operating effectively and systems are being managed appropriately.

The areas that the review sought to provide assurance on were:

- the networks responsibility to carry out the duties required of them to manage and lead the planning and performance management of the renal service contracts,
- whether the governance framework for the network is operating effectively

The monitoring of the action plan is through the WKN Board.

The final report together with its recommendations were presented to the Joint Committee in <u>January 2023</u>.

The report made comments regarding the working arrangements of the Network and made 11 recommendations to strengthen the governance arrangements of

the network. The updated Terms of Reference addressed some of recommendations and were endorsed by the WKN Board in April 2023, and will be presented to 16 May 2023 JC for final approval.

The Independent Advisor identified some other issues for consideration and concluded that:

"In the medium term there is a need to confirm the strategic direction of the Network. As indicated this is a challenging agenda and needs to be undertaken in conjunction with Welsh Government colleagues, given the changing landscape at an All-Wales level with the creation of the NHS Executive".

# The Review concluded that:

"It is clear that the Renal Network has achieved a great deal since it was established and the service to patients has improved enormously. It has been successful at working as a managed network rather than a commissioner of services and caution is needed at this stage not to create increased bureaucracy and stifle the innovative approach the Network has taken."

It is important to note that since the WKN was established in 2009, it has matured and widened its scope of activity. In addition, there have been significant changes to the governance environment within the NHS in Wales; the future direction of the WKN will be considered further during 2023.

On <u>12 July 2022</u>, the Joint Committee ratified the decision of the Welsh Renal Clinical Network (WRCN) Board to change the name of the WRCN to the "Welsh Kidney Network".

# 2.2.2 Advisory Groups and Networks

During 2022-2023, the Joint Committee had one established advisory group in place to support the discharge of its functions:

 All Wales Mental Health and Learning Disability Collaborative Commissioning Group

At its meeting in May 2022, the Joint Committee supported the disestablishment of the NHS Wales Mental Health and Learning Disability Collaborative Commissioning Group.

#### 2.3 Joint Committee and Joint Sub-Committees Meetings

It is acknowledged that in the unprecedented times since the COVID-19 pandemic, there have continued to be limitations on Boards and Committees being able to physically meet where this is not necessary and can be achieved by other means. In accordance with the Public Bodies (Admissions to Meetings) Act 1960 the Joint Committee is required to meet in public.

As a result of the public health risk linked to the pandemic when there were limitations on public gatherings and it was not therefore possible to allow the

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public to attend meetings of the Joint Committee, virtual meetings were introduced to ensure business was conducted in as open and transparent manner.

Further to the Committee effectiveness exercise for 2021-2022 undertaken in April 2022, the feedback from individual members indicated that the majority of members preferred to continue with the virtual meeting arrangements adopted during the COVID-19 pandemic and the recovery phase. Therefore, for the foreseeable future all Joint Committee and sub-committee meetings continued to be held virtually during 2022-2023 and face to face meetings were considered for any key decision making requirements as deemed appropriate by the Chair. Arrangements were in place to ensure that the decision logs were maintained and reported to each meeting appropriately.

Virtual meetings and electronic communication have remained the key to the Joint Committee's functionality as we adapt our working practices following the COVID-19 pandemic.

To ensure business is conducted in as open and transparent a manner as possible, the following actions were taken:

- Joint Committee papers were routinely published and made available on the WHSSC website two weeks prior to meetings, so far as possible,
- Written briefings of the key components of meetings were published as soon as possible after meetings.

The website (which gives our official notice of Joint Committee meetings) includes a statement inviting anybody wishing to attend a Public meeting to contact the organisation in advance to determine suitable arrangements. During the Joint Committee meeting held on <a href="https://doi.org/10.2023/journal.org/10.2023/">17 January 2023</a> a member of the public observed the public meeting via Microsoft Teams.

The membership of the Joint Committee and member's attendance is presented at **Appendix 1.** A table outlining the dates of Joint Committee meetings held during 2022-2023, is presented at **Appendix 2.** 

# 2.4 Committees of the Host Organisation

#### 2.4.1 Audit & Risk Committee

The Audit & Risk Committee of Cwm Taf Morgannwg University Health Board (CTMUHB), as host organisation, advises and assures the Joint Committee on whether effective arrangements are in place, through the design and operation of the Joint Committee's assurance framework. This supports members in their decision taking and in discharging their accountabilities for securing the achievement of the Joint Committee's Delegated Functions.

Relevant officers from WHSSC attend Part B CTMUHB Audit & Risk Committee meetings for agenda items concerned with WHSSC business. An assurance report following each Part B meeting is submitted to the Joint Committee outlining the business discussions for assurance.

# 2.4.2 CTMUHB Quality & Safety Committee

<u>The Quality & Safety Committee of CTMUHB</u>, as host organisation, advises and assures the Joint Committee on the provision of workplace health & safety within WHSSC.

Relevant officers from WHSSC attend the CTMUHB, Quality & Safety Committee when appropriate.

#### 2.5 Standards of Behaviour

The Welsh Government's *Citizen-Centred Governance Principles* apply to all public bodies in Wales. These principles integrate all aspects of governance and embody the values and standards of behaviour expected at all levels of public services in Wales.

# "Public service values and associated behaviours are and must be at the heart of the NHS in Wales"

The Joint Committee is strongly committed to WHSSC being value-driven, rooted in the Nolan principles and high standards of public life and behaviour, including openness, customer service standards, diversity and engaged leadership.

The Joint Committee expects all Members and employees to practice high standards of corporate and personal conduct, based on the recognition that the needs of service users must come first.

The "Seven Principles of Public Life" or the "Nolan Principles" form the basis of the Standards of Behaviour requirements for WHSSC employees and Independent Members.

The WHSSC Standards of Behaviour Policy, incorporating Declarations of Interest, Gifts, Hospitality and Sponsorship, aims to ensure that arrangements are in place to support employees to act in a manner that upholds the Standards of Behaviour Framework. In addition, it sets out specific arrangements for the appropriate declarations of interests and acceptance / refusal and record of offers of Gifts, Hospitality or Sponsorship. The Policy also aims to capture public acceptability of behaviours of those working in the public sector so that WHSSC can be seen to have exemplary practice in this regard.

The WHSSC Standards of Behaviour Policy was approved on 13 January 2021 and a copy of this policy can be found on the WHSSC website.

https://whssc.nhs.wales/publications/corporate-policies-and-procedures/

In accordance with the WHSSC Standards of Behaviour Framework Policy and Standing Orders WHSSC issued requests for annual Declarations of Interest returns for the 2022 -2023 financial year on 23 March 2023. For 2022-2023, the

DOI form was updated to align the Health Board processes and our DOI process has been strengthened to include cross-referencing information with the Companies House register and any other related declaration processes.

The register of interests is available on request or through the WHSSC publication scheme on the WHSSC website:

https://whssc.nhs.wales/publications/governance

#### 3.0 THE PURPOSE OF THE SYSTEM OF INTERNAL CONTROL

The system of internal control is designed to manage risk to a reasonable level rather than to eliminate all risks; it can therefore only provide reasonable and not absolute assurances of effectiveness.

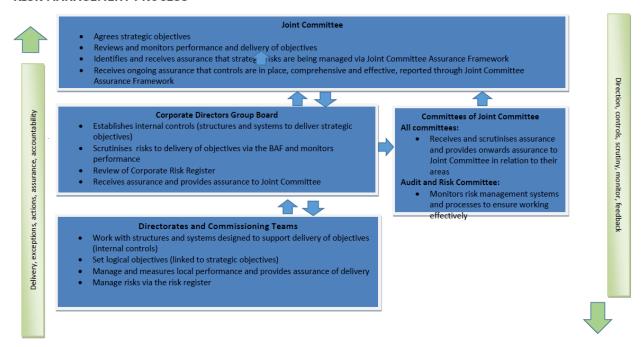
The system of internal control is based on an ongoing process designed to identify and prioritise the risks to the achievement of the policies, aims and objectives, to evaluate the likelihood of those risks being realised and the impact should they be realised, and to manage them efficiently, effectively and economically. The system of internal control was in place for the year ended 31 March 2023 and up to the date of approval of the annual accounts.

#### 4.0 CAPACITY TO HANDLE RISK

The WHSSC systems of control are designed to manage risk to a reasonable level rather than to eliminate all risks; it can therefore only provide reasonable and not absolute assurance of effectiveness.

The WHSSC system of control is based on an ongoing process designed to identify and prioritise the risks to the achievement of its policies, aims and objectives, to evaluate the likelihood of those risks being realised and the impact should they be realised, and to manage them efficiently, effectively and economically. The system of internal control has been in place for the year ended 31 March 2023 and up to the date of approval of the CTMUHB annual report and accounts.

#### RISK MANAGEMENT PROCESS



#### 4.1 The Risk and Assurance Framework

Risk management is embedded in the activities of WHSSC through the WHSSC Risk Management Framework and associated operating procedures. Overall responsibility for the Risk Management lies with the Director of Planning and Committee Secretary who have delegated responsibility for managing the development and implementation of the Risk Management Strategy. Arrangements are in place to effectively assess and manage risks across the organisation, which includes the ongoing review and updating of the CRAF so that the Joint Committee maintains a line of sight on the WHSSC's key strategic and operational risks.

WHSSC's Risk Management Strategy sets out responsibilities for strategic and operational risk management for the Joint Committee and staff throughout the organisation and describes the procedures to be used in identifying, analysing, evaluating and controlling risks to the delivery of strategic objectives. A revised Risk Management Strategy was approved by the Joint Committee on 11 May 2021 and aligns to the Risk Management Strategy agreed by CTMUHB (WHSSC's host organisation) for consistency.

The Corporate Risk and Assurance Framework (CRAF) forms part of WHSSC's approach to the identification and management of strategic and other top-level risks. The framework is subject to continuous review by the Executive Director lead for each risk, the Corporate Directors Group Board (CDGB), the joint subcommittees and the Joint Committee.

The CRAF is informed by risks identified by both Directorates and Commissioning Teams that are considered by a bi-monthly risk scrutiny panel that reports to CDGB. Each risk is allocated to an appropriate sub-committee for assurance and

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monitoring purposes. The CRAF is received by the sub-committees as a standing agenda item, and the Joint Committee receives the CRAF at least twice yearly and this was last received by the Joint Committee on 17 January 2023.

The CRAF is an integral part of the system of internal control and defines the extreme potential risks listed on the Corporate Risk Register (scored 15 or above) which may impact upon the delivery of strategic objectives. It also summarises the controls and assurances that are in place or plans to mitigate them. The CRAF aims to align principal risks, key controls and assurances on controls alongside each of WHSSC's strategic objectives.

Each directorate risk register is submitted to the Risk Scrutiny Group (RSG) on a bi-monthly basis. The membership of the RSG includes Directorate Managers who review and scrutinise the narrative, scores and mitigating actions for each risk. The risks are validated by the RSG and are subject to continuous review by the Executive Director lead for each risk. In addition to reviewing Directorate Risks, the RSG also receives a deep dive into a Commissioning Team Risk Register at each of its meetings.

A risk management workshop was held on 20 September 2022 to assess how the Risk Scrutiny Group (RSG) process was working, to consider risk appetite and tolerance levels across the organisation and to discuss developing a Joint Assurance Framework (JAF).

The aims of the risk workshop were to:

- Clearly define WHSSC's Risk Appetite Statement,
- Clearly define WHSSC's Risk Tolerance Levels,
- Horizon scan and assess any potential new risks; and
- Discuss next steps for risk management.

Each directorate competed a SWOT (Strengths, Weaknesses, Opportunities and Threats) analysis to identify good practice and achievements and to horizon scan for new and emerging risks.

On 14 December 2022, the CDGB undertook a thorough review of all of the findings from the risk workshop and identified new risks which were included in the December 2022 CRAF. In addition, the WKN undertook a review of their Risk register and they have migrated the WKN risks onto the WHSSC risk template.

The updated CRAF was approved by the Joint Committee on <u>17 January 2023</u>. The risks outlined in *Table 1* below were identified as posing the greatest risk (20 and above) to the delivery of the WHSSC's commissioning objectives during 2022-2023:

Table 1 – High coring Risks 20 and above

Ref	Risk Description	Risk Score
<b>23</b> (MH/21/08)	Access to Care Adults with a Learning Disability There is a risk that adults with a learning disability will not have access to appropriate care and treatment due to the lack of secure MH beds in Wales and a reduction in access to beds in England.	20 (5x4)
<b>24</b> (MH/21/09)	Access to Care Children with a Learning Disability There is a risk that children with a learning disability will not have access to appropriate care and treatment due to the lack of secure MH beds in Wales and a reduction in access to beds in England. The consequence is that patients may be inappropriately placed with the potential to receive sub-optimal care.	20 (5x4)
<b>29</b> (CS/08 CD02)	There is a risk that WHSSC will be unable to meet the TOR for the All Wales IPFR panel due to the inability to achieve quoracy in the membership and consequently this may lead to delayed decision-making. In addition, there is also a risk that the current IPFR governance arrangements are not robust and consequently this may also lead to legal challenges in the form of judicial reviews.	20 (4x5)
<b>33</b> (CS/10 CD03)	Welsh Government Priority Delivery Measures There is a risk the Welsh Provider Health Boards will not be able to deliver specialised services in line with the new Priority Measures due to the waiting list backlog and the shortfall in capacity as a consequence the measures will not met, patients will be waiting outside of the waiting times within the measures and WHSSC may need to seek commissioning alternatives.	20 (4×5)
<b>34</b> (P/21/16)	Lack of Paediatric Intensive Care Beds There is a risk that a paediatric intensive care bed, in the Children's Hospital for Wales, will not be available when required due to constraints within the service. There is a consequence that paediatric patients requiring intensive care will be cared for in, inappropriate areas where the	20 (4x5)

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necessary skills or equipment are not available or the patient being transferred out of Wales.

In April 2023 as part of the annual internal audit programme and internal audit was undertaken to evaluate and determine the adequacy of the systems and controls in place within WHSSC in relation to risk management. Internal audit gave an audit assessment rating of reasonable assurance" and concluded that WHSSC has an up to date and comprehensive risk management strategy in place that clearly sets out roles and responsibilities.

The CRAF is continuously reviewed in line with the Risk Management Strategy and is being further strengthened to incorporate the recommendations of the internal audit feedback.

WHSSC is committed to continuous improvement across the whole risk management pathway, areas of significant focus for 2023 include:

- Developing and implementing the new Joint Committee Assurance Framework (JAF) and reviewing the Risk management Strategy,
- Training and awareness of the risk management process; and
- Implementing the Once for Wales Risk Management System (Datix Cloud System) and aligned training programmes.

# 4.2 Risk Appetite

Members of the WHSSC Joint Committee share responsibility for the effective management of risk and compliance with relevant legislation. In relation to risk management, Joint Committee is responsible for approving the risk appetite for WHSSC. The WHSSC risk management strategy states that the Joint Committee will review its risk appetite on an annual basis to ensure that progress is being made toward the 'risk appetite' WHSSC wishes to achieve. Following the risk workshop the CDGB reviewed its risk appetite and an updated risk appetite statement 2023 was approved by the Joint Committee on 17 January 2023.

WHSSC's risk appetite has been defined following consideration of organisational risks, issues and consequences. To assess risk appetite the <u>Good Governance Institute's Matrix for NHS Organisations</u> was followed. Appetite levels will vary, in some areas, our risk tolerance may be cautious in others we may be eager for risk and are willing to carry risk in the pursuit of important strategic objectives. WHSSC will always aim to operate organisational activities at the levels defined below.

Where activities are projected to exceed the defined levels, this will be escalated through the appropriate governance mechanisms to the Joint Committee for ratification.

**Table 2** below outlines the risk appetite.

Table 2 – WHSSC Risk Appetite

Type of Risk	Risk Appetite	
Innovation/Quality Outcomes	WHSSC has adopted a Cautious stance for quality and safety risks, with a preference for safer delivery options, tolerating a cautious degree of residual risk and choosing the option most likely to result in successful delivery, high quality care and value for money services to its population.	
Reputation / Adverse Publicity (Trust in Confidence) risks	WHSSC has adopted a Cautious stance for reputational risks, with a preference for safer delivery options, tolerating a cautious degree of residual risk and choosing the option most likely to result in successful delivery, high quality care and value for money services to its population.	
Business Continuity risks	WHSSC has adopted a Cautious stance for Business Continuity Risks. The Joint Committee will receive ongoing assurance from the testing of business continuity plans	
Compliance/Regulatory risks	WHSSC has adopted a Cautious stance for Legal, Regulatory and Compliance risks, seeking a preference for adhering to responsibilities and safe delivery options with little residual risk. The joint Committee will receive assurance that compliance regimes are in place	
Data and Information  Management risks	WHSSC has adopted a Cautious stance for data and information management risks seeking a preference for adhering to responsibilities and safe delivery options with little residual risk. There is acceptance for the need for operational effectiveness with risk mitigated through careful management of information sharing and limiting distribution	
Financial stability risks/VFM	<ul> <li>WHSSC stance for financial risk is varied as follows:         <ul> <li>Averse for financial propriety and regularity risks with a determined focus to maintain effective financial control framework accountability structures.</li> <li>Averse – in terms of risks related to WHSSC qualification of accounts, associated process and deviation from reporting timescales.</li> <li>Minimal – as to risk relating to breaching individual control totals.</li> <li>Cautious – in relation to the WHSSC budget spend with the intention that it should maximise the use of resource each year. WHSSC will seek safe delivery options with little residual risk that only yield some upside opportunities. WHSSC would receive ongoing assurance through reporting structures that policies</li> </ul> </li> </ul>	

Type of Risk	Risk Appetite		
	and procedures are in place to comply with HMT guidance.		
Assets and Estates risks –	WHSSC has adopted Cautious and Open stances for assets and estates respectively, seeking value for money but with a preference for proven delivery options have that a cautious residual risk. this means that WHSSC will use solutions for purchase, rental, disposal, construction, and refurbishment that ensures it protects the public purse from as much risk as possible, producing good value for money whilst fully meeting organisational objectives.		
Technological advances	WHSSC has adopted an Open stance for risks associated with technological advances accepting that system and technology developments can enable improved delivery. Responsibility for non-critical decisions may be devolved in accordance with the Scheme of Delegation. Plans aligned with functional standards and organisational governance.		

#### 4.3 Joint Assurance Framework

WHSSC is committed to developing and implementing a Joint Assurance Framework (JAF) that identifies, analyses, evaluates and controls the risks that threaten the delivery of its strategic objectives. The JAF will be considered alongside the CRAF, performance and quality dashboards and financial reports, to give the Joint Committee a comprehensive picture of the organisational risk profile. The intention is that the JAF also aligns with the new Specialised Services Strategy. It is anticipated that the Strategy will be in place by the end of 2023.

#### 5.0 THE CONTROL FRAMEWORK

#### 5.1 Performance Dashboard

Prior to the COVID-19 pandemic WHSSC had two performance dashboards. An Organisation Performance Report and an Integrated Performance Report. Compilation and monitoring of these was stood down during the pandemic.

As a result of responding to the COVID-19 outbreak, provider organisations were permitted to stand down routine care and focus on delivery of services for patients with COVID-19 and essential services. During the height of the pandemic, it was difficult to engage with providers who were heavily focused on the pandemic. To overcome this, WHSSC adopted a direct monitoring system and reviewed available performance data.

V-0.11 Page 23 of 55 WHSSC Annual Governance Statement 2022-2023 The Joint Committee held a workshop on "Recovery Trajectories across NHS Wales" at its meeting on 12 July 2022. Members received presentations on the recovery trajectories across Wales and the monitoring of recovery data was a key issue for the Joint Committee throughout 2022-2023.

The Recovery Trajectories presentations from the NHS Wales Delivery Unit, Betsi Cadwaladr UHB (BCUHB), Swansea Bay UHB (SBUHB) and Cardiff & Vale (CVUHB) encouraged wide-ranging discussion and a focus on Paediatric Recovery was presented at the <a href="November 2022">November 2022</a> JC meeting.

Since the COVID-19 outbreak, WHSSC has taken an activity report to each Joint Committee and Management Group that seek to highlight the scale of the decrease in activity levels during the peak COVID-19 period, and report whether there are any signs of recovery in specialised services activity. The activity decreases were also shown in the context of the potential risk regarding patient harms and of the loss of value from nationally agreed financial block contract arrangements.

The reports evolved and during 2022-2023 included more explicit, measureable intentions to measure achievements against and additional detailed analysis of the position and any key points to promote effective focus and discussion.

Detailed activity performance reports are prepared on a monthly basis and provide qualitative information and quantitative data to the Joint Committee and Management Group meetings. The reports detail delivery by provider and specialty against historic performance and waiting times. Prospective activity reports will also include performance compared to provider agreed recovery plans and waiting list profiles. A presentation dashboard format of the waiting times position has been agreed and details variation from agreed activity delivery, referral rates and overall waiting lists whenever possible. The activity dashboard has already been adapted and aligns to the Welsh Government Priority Delivery Measure.

The WHSSC Commissioner Assurance Framework (CAF) sets out a performance assurance process alongside more outcome focussed performance measures. Monitoring recovery from the pandemic required a different approach. Reviewing data on patient outcomes became an important part of these Performance Management arrangements.

Assurance against the CAF is achieved through service specifications, Service Level Agreements (SLA) and performance monitoring through Quality and Patient Safety Committee (QPSC) and the Integrated Governance Committee (IGC).

The suspension of the referral to treatment targets (RTTs) set by Welsh Government impacted the way that commissioned services were monitored and

created a need to temporarily revise the reporting of services in escalation because of a failure to meet RTTs.

WHSSC responded to the request for a relaxed framework by:

- Relaxing the formal focus of SLA meetings (reporting and assurance on contracts, activity and cost) to a less formal approach (reporting on recovery, anticipated trajectories, and general) updates; and
- Moving traditional service level performance management meetings to commissioner assurance meetings.

Given the pandemic and pressures on providers, services in escalation for isolated RTT failures were removed from the escalation process. Commissioning teams continued to work closely with providers and maintained oversight of their recovery plans and trajectories.

Alongside the measures set out in the Ministerial Priorities, WHSSC continues to work closely with providers to assess performance against contracts, to develop plans to address any variance, and where appropriate to find alternate means of provision (e.g. outsourcing) where necessary to ensure that the population needs are met.

During 2022-2023, there has been a further period of tolerance as the system has moved from crisis into recovery, and financial frameworks gradually moved from block back to being based on activity and performance.

Alongside Welsh Government's (WG) shift back to a robust performance management approach, WHSSC has also signalled its intention to do likewise, and now needs to recalibrate its performance management arrangements, redefine the roles and responsibilities of differing parts of the performance management system; and bring standardisation across performance management levels with all providers, and ultimately re-develop the performance management framework.

An updated Performance Management Framework was supported at the April 2023 Management Group meeting and a final version will be presented to the May 2023 JC for approval. From April 2023, there will be a return to monthly performance reporting to Management Group and Joint Committee.

There are 3 levels at which performance management discussions between WHSSC and provider HBs take place, and upon which the Performance Management arrangements have been built: Strategic, Planning and Performance. The performance framework hierarchy is outlined in **Table 3** below:

<u>Table 3 – Performance Framework Hierarchy</u>

Level of	Meeting	Purpose
discussion		
Strategic	Board to Board Exec to Exec	<ul> <li>Strategic direction</li> <li>Strategic risks</li> <li>Strategic appetite for service developments</li> <li>Strategic discussion on population health, equity, access etc.</li> <li>Enabling delivery</li> </ul>
Planning	Planning team to HB corporate teams	<ul> <li>Monitor progress with development of Integrated Commissioning Plan (ICP) and Integrated Medium Term Plans (IMTPs) Identify barriers/risks to implementation of plan and developments contained therein</li> <li>Share intelligence in order to triangulate workforce, finance and performance improvement</li> <li>Ensure there are 'no surprises' on performance and delivery issues</li> </ul>
Performance	SLA Meetings  Service level performance meetings	<ul> <li>Formally manage and escalate variation in performance on quality, activity, delivery of Ministerial measures and financial performance.</li> <li>Formally receive exception reports on services in Escalation</li> <li>Deal with issues escalated from the service level performance meetings</li> <li>Formally note and monitor investments and benefits</li> <li>To monitor performance in individual service areas –</li> </ul>
	performance meetings	including quality, activity, Ministerial and service specification measures and financial performance  To monitor investments and benefits

Level of discussion	Meeting	Purpose	
		<ul> <li>To escalate issues as needed to the SLA meeting with Health Boards</li> </ul>	
	Escalation	<ul> <li>To enable development of an action plan for those services in escalation</li> <li>To enable monitoring of necessary actions</li> </ul>	
		To enable de-escalation	

From a financial and contracting point of view during 2022-2023 there has been a further period of tolerance as the system has moved from crisis into recovery, and financial frameworks gradually moved from block back to being based on activity and performance. The Directors of Finance Peer Group has indicated a preference to retain a level of tolerance in 2023/24 (although reduced) and this will be discussed further with the Joint Committee.

#### **5.2 Ministerial Priorities & Measures**

Following the pandemic the Minister for Health and Social Services published new priority measures in January 2022, and all NHS organisations were required to report on the new measures from April 2022. The process WHSSC adopts to respond to the measures was approved by the Joint Committee on  $\underline{15~\text{March}}$   $\underline{2022}$ .

Whilst many of the 32 measures require monitoring of provider performance by WHSSC, others could be referenced in various contracts/policies (i.e. those related to infection prevention and control). There are also some measures that, whilst not directly attributable to specialist services provision, could have a longer-term impact on demand (e.g. measures on weight loss could, in the longer term, impact the need for bariatric surgery).

In the Accountability Conditions letter sent in response to the submission of the ICP 2022/23 the Director General required WHSSC to focus on the equity of access in six key specialty areas and, as reported in section 5.1 trajectories were requested from providers for these areas and have been monitored and reported through our performance reporting since September 2022. We have also used our Escalation Framework in a number of these areas to support further improvement.

The mechanisms between WHSSC and commissioned providers continue to be utilised for measuring the Ministerial Measures as set out in the Performance Management Framework (see section 5.1).

# 5.3 Integrated Commissioning Plan (ICP) for Specialised Services

V-0.11 Page 27 of 55 WHSSC Annual Governance Statement 2022-2023 Each year Welsh Government issues the NHS Planning Framework to support statutory organisations within NHS Wales to meet their legal duty to develop an integrated medium term plan, which aligns service, workforce and finance plans. The ICP responds to the Framework and presents a cohesive plan for the commissioning of Specialised Services for the people of Wales.

The ICP is developed by the Welsh Health Specialised Services Committee (WHSSC) on behalf of the seven Health Boards (HBs) in Wales, and is the basis upon which HBs will plan for specialist services provision within their Integrated Medium Term Plans (IMTPs). Once again, this year the ICP has been developed in the context of the extreme financial pressures and service challenges facing NHS Wales. In January 2023, a Review of National Commissioning Functions was announced by Welsh Government which will conclude in April 2023. In addition work on developing a Specialist Services Strategy continues, with the aim of agreeing the Strategy in the context of the recommendations of the National Commissioning review in 2023.

The Joint Committee (JC) approved the Integrated Commissioning Plan (ICP) on the <u>13 February 2023</u>. The plan for 2023-24 includes the conclusion of the work on our Specialised Services Strategy and the implementation actions from our two agreed service commissioning strategies (Mental Health and Specialised Paediatrics) with the Specialised Haematology Services Review.

In year, we will develop a further service commissioning strategy for specialised rehabilitation and commence the review of cardiac services in South Wales. Due to the difficult financial climate, there are smaller number than usual of prioritised service developments but all of the high priority horizon -scanning schemes have been included in the Plan.

The IGC plays a key role in monitoring implementation of each ICP. From August 2022 the IGC received quarterly updates on progress on delivering the Integrated Commissioning Plan 2022-23 which was developed to respond to the Welsh Government requirements as set out in the NHS Planning Guidance 2021.

### 5.4 A Specialised Services Strategy for Wales

Whilst the development of the ICP takes place in accordance with the NHS Wales planning cycle, through discussions with Joint Committee, WHSSC has committed to developing an overarching 10 year Specialised Services Strategy for Wales.

The last specialised services strategy was published in 2012. During the intervening period there has been significant challenge related to the pace of development of innovative treatments, an increasingly austere financial climate, the unprecedented and disruptive impact of the COVID-19 pandemic on NHS care and the recent extreme financial pressures facing the NHS. The policy context within NHS Wales has also changed during this time and any strategy will need to be aligned to a number of major policy developments.

Further to the Welsh context, in July 2022, the Health and Care Act 2022 for NHS England legally established 42 Integrated Care Systems (ICSs) which will plan and manage health and care services in their ICS area, including more integrated commissioning of specialised services from April 2023.

Recommendation 4 within the Audit Wales report "WHSSC Committee Governance Arrangements" published in May 2021 made a recommendation that WHSSC should develop and approve a new strategy during 2021. Work began to develop a new strategy, however became delayed due to the refocussed activities of WHSSC business and personnel during the Omicron wave of the COVID-19 pandemic.

A Project Manager led the work required to develop and agree the specialised services strategy. As agreed at Joint Committee meeting on <u>6 September 2022</u>, a 12 week engagement process was undertaken during October and December 2022 to inform and support the development of a ten year specialised services strategy.

The engagement approach taken was a blend of written and electronic feedback via an online survey from our stakeholders. The survey questions were built around 3 strategic themes – What, Where and How. Stakeholders were identified and actively engaged to encourage their participation in the survey in addition to gathering general feedback through a series of meetings that were carried out.

A high level analysis of the thematic responses was developed and shared with Management group at its February 2023 meeting. A set of strategic aims and objectives were developed and these were presented at the March 2023 MG meeting.

It is envisaged that the work will be completed and approved by the Joint Committee on 16 May 2023 and published on 31 May 2023.

#### **6.0 DISCLOSURE STATEMENTS**

# 6.1 Equality, Diversity & Human Rights

Equality is central to the work of WHSSC and our vision for improving and developing specialised services for NHS Wales. WHSSC welcomes Welsh Government's distinct approach to promoting and safeguarding equality, social justice and human rights in Wales. WHSSC is committed to complying with the provisions of the Equality Act 2020, and the public sector general duty and the specific duties to promote and safeguard equality, social justice and human rights in Wales. We are committed to ensuring and considering how we can positively contribute to a fairer society through advancing equality and good relations in our day-to-day activities

WHSSC follows the policies and procedures of CTMUHB, as the host LHB, which set out the organisational commitment to promoting equality, diversity and human rights in relation to employment. It also ensures staff recruitment is conducted in an equal manner. All staff have access to the Intranet where these are available. The Hosting Agreement includes provision for specific support around Equality and Diversity.

The Corporate Services Manager is a member of the Equality and Welsh Language Steering Group within CTMUHB and any issues are integrated into this process.

Following the publication of the WG Anti-Racist Wales action Plan in June 2022, our host CTMUHB have issued an invitation for all staff (including WHSSC) to respond to an audit and focus group being undertaken by "Diverse Cymru" on behalf of WG, of NHS workforce policies through an anti-racist lens. This work was identified as a priority action in the <a href="Anti-racist Wales Action Plan.">Anti-racist Wales Action Plan.</a>

The Welsh Government's Public Sector Equality Duty (PSED) advocates that all public sector organisations publish their Strategic Equality Plan (SEP) no less than every four years. Whilst WHSSC commissions specialised services on behalf of the seven LHBs the responsibility for individual patients remains with the LHB of residence.

#### 6.2 Welsh Language

WHSSC is committed to treating the English and Welsh languages based on equality and will endeavour to ensure the services we commission meet the requirements of the legislative framework for Welsh Language as required by the Welsh Language Act (1993), the Welsh Language (Wales) Measure 2011 and the Welsh Language Standards (No. 7) Regulations. Provider organisations in Wales are subject to the same legal framework, however the provisions of the Welsh language standards do not apply to services provided in private facilities or in hospitals outside of Wales. In recognition of its importance to the patient experience, WHSSC ensures that wherever possible patients have access to their preferred language. This commitment is now set out as an overarching statement in all new and updated WHSSC commissioning policies and service specifications.

In order to facilitate this WHSSC is committed to working closely with providers so that in the absence of a welsh speaker in the service, patients and their families will have access to either a translator or 'Language-line'. We will also encourage, in those services where links to local teams are maintained during the period of care, that this will provide, when possible, access to the Welsh language.

During 2022-2023, the Corporate Services Manager and Committee Secretary were invited to attend the newly established CTMUHB Welsh Language Steering Group meetings to lead and drive the implementation and delivery of legislative Welsh Language compliance across WHSSC and supports implementation of the "More than just words" framework. The Committee is a sub-committee of the CTMUHB People and Culture Committee. The purpose of the Committee is to

support the CTMUHB Board to deliver on its responsibilities, in accordance with the legislative framework for Welsh Language, and to improve service user experience, through the provision of bilingual care and support. The first meeting took place on 15 March 2023.

# **6.3 Well-Being of Future Generations Act (WBFGA)**

The Well-being of Future Generations Act (WBFGA) requires named statutory bodies, including CTMUHB, (our host) to ensure the needs of the current population are met without compromising the ability of future generations to meet their own needs. This 'sustainable development principle' requires the organisation to routinely follow the five ways of working from the Act (prevention, long-term, collaboration, integration, involvement), and contribute to the seven national well-being goals.

WHSSC is committed to contributing towards the achievement of the objectives of the Well-being of Future Generations (Wales) Act aims to improve the social, economic, environmental and cultural well-being of Wales. The WBFGA gives us the opportunity to think differently and to give new emphasis to improving the well-being of both current and future generations, and to think more about the long-term, work better with people, communities and organisations, seek to prevent problems and take a more joined-up approach. This Act puts in place seven well-being goals, and we need to maximise our contribution to all seven.

The ICP integrates and demonstrates the five ways of working and contribution to well-being goals throughout the plan. Prevention is embedded throughout our work.

The back cover for Committee reports includes a section for the author to consider Organisational Implications and outline any legal implications, including the WBFGA.

# **6.4 Socio Economic Duty**

WHSSC recognises that the Socio-economic Duty introduced by Welsh Government under the Equality Act 2010 requires relevant public bodies in Wales, which include LHB's, to have due regard to the need to reduce the inequalities of outcome that result from socio-economic disadvantage when they take strategic decisions. The duty came into force on 31 March 2021 and as a Joint Committee of the LHB's, this duty has been taken into account when planning and commissioning specialised services. WHSSC will consider how their decisions might help reduce the inequalities associated with socio-economic disadvantage, including evidencing a clear audit trail for all decisions made that are caught by the duty. This will be discharged by using existing processes, such as engagement processes and impact assessments.

#### 6.5 Health and Care Standards

The Health and Care Standards sets out the Welsh Government's common framework of standards to support the NHS and partner organisations in

providing effective, timely and quality services across all healthcare settings. They set out what the people of Wales can expect when they access health services and what part they themselves can play in promoting their own health and wellbeing.

The Health and Care Standards are focussed around service delivery and therefore a number of areas are not relevant to the remit of WHSSC. However, WHSSC has sought opportunities to ensure consideration of the standards within its work and requires all reports to the Joint Committee and sub-committees to identify which themes within the Health and Care Standards were considered/appropriate when developing those reports. In particular, WHSSC has appropriate structures and processes in place to meet the requirements of the Governance, Leadership and Accountability standard through its Governance and Accountability Framework, ICP process and escalation process.

# 6.6 Duty of Quality

The duty of quality comes into legal force in April 2023 in line with the Health and Social Care (Quality and Engagement) (Wales) Act 2020. The new reporting requirements will be captured in processes in place for 2023-24.

# 6.7 Duty of Candour

The duty of candour comes into legal force in April 2023 in line with the Health and Social Care (Quality and Engagement) (Wales) Act 2020. It requires them to be open and transparent with service users when they experience harm whilst receiving health care.

On 3 October 2022 the Corporate Directors Group Board (CDGB) received a briefing from Welsh Government (WG) on the Health & Social Care (Quality & Engagement) (Wales) Act 2022 with a specific focus on the consultation process for the duty of candour and the soon to be launched consultation process on the duty of quality. The session gave an insight into the need to focus on quality-driven decision-making to improve outcomes and the need to demonstrate with evidence how we have complied with the duty. In addition, to the need to comply with the duty of candour in relation to health care provision. It was recognised that we already have good systems and processes in place on which we can build for both the duties.

#### **6.8 Emergency Preparedness**

As previously highlighted, the need to plan and respond to the COVID-19 pandemic presented a number of challenges to WHSSC. A number of new and emerging risks where identified. Whilst WHSSC did have a business continuity plan in place, as required by the Civil Contingencies Act 2004, the ongoing scale and impact of the pandemic has been unprecedented.

In terms of delivering commissioned services, significant action has been taken in collaboration with the HBs and provider in NHS England to prepare and respond to the likely impact on the organisation and population. There does remain a level of uncertainty about the overall impact this will have on the immediate and longer-term delivery of commissioned services by the WHSSC, although we are confident that all appropriate action is being taken.

WHSSC continues to work closely with CTMUHB on business continuity planning arrangements.

WHSSC are working in partnership with HBs and utilise their recovery plans to influence our Integrated Commissioning Plan (ICP). This is supported by a robust risk management framework and the ability to identify, assess and mitigate risks that may impact on the ability to achieve our strategic objectives.

#### 6.9 Carbon Reduction

Welsh Government declared a Climate Emergency in 2019 and expects the public sector to be net zero by 2030. The <a href="NHS Wales Decarbonisation Strategic Delivery Plan">NHS Wales Decarbonisation Strategic Delivery Plan</a> was published on 24 March 2021.

WHSSC is committed to taking assertive action to reducing the carbon footprint through mindful commissioning activities, where possible providing services closer to home (via digital and virtual access where possible) and ensuring a delivery chain for service provision and associated capital that reflects our commitment. We will also seek to support staff considerations and behaviours for those actions that have a positive effect on decarbonisation for example reduced travel, efficient travel and use of electric vehicles where possible. With effect the commencement of the 2022-2023 year, all corporate policies will have a decarbonisation statement contained within.

WHSSC is committed to reducing the carbon footprint through mindful commissioning of services that take account the decarbonisation agenda, enabling enhanced digital and virtual access for patients and through ethical consideration of staff actions and behaviours e.g. reduced travel, increased use of virtual engagement and, where feasible, use of electric vehicles. From 2022, all WHSSC commissioning policies will have a focus on innovative ways of working including digital and remote clinics to support reducing the carbon footprint.

In particular during 2023 and beyond WHSSC continue to embed the working practices that were, by necessity, introduced in 2020. In particular WHSSC have adopted a blended and hybrid approach to office and remote working, reducing the need for travel, and we continue to run as many meetings as practically possible using online platforms inlcuding Microsoft Teams. Additionally, many of the WHSSC systems which moved to paperless processes have continued operating in this way and these have proven to be more efficient and reduces our impact on the environment. We will continue do adopt these practices going forward.

Increasing numbers of staff are purchasing electric vehicels via the NHS Fleet Solutions Scheme. As a consequence, WHSSC installed EV charging stations at its premises on 20 April 2022.

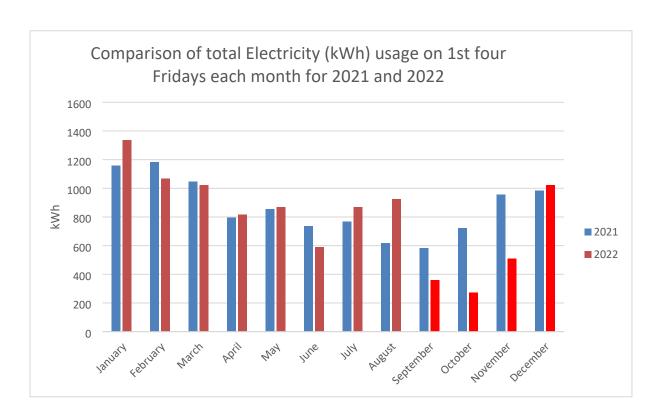
All our Electricity is Zero Carbon procured on an all-Wales basis under the Renewable Energy Guarantees of Origin (REGO) scheme. We have a smart meter installed and during 2022-2023 we monitored our office utilities and through the introduction of a Friday office closure we have been able to meet the Welsh Government 3% reduction target on the office energy use since this was introduced in September 2022.

The below graph findings compares electricity usage for first four Fridays only per month for 2021 and 2022. The electricity usage is calculated by KWh.

Office closure periods have been highlighted in red. Office closure started on Friday 2 September 2022.

#### The key points are:

- September 2022 38% lower than September 2021,
- October 2022 is 62% lower than October 2021,
- November 2022 47% lower than November 2021, (this measures the impact of the Friday closure).
- December 2022 was slightly higher than 2021 due to staff being in on Fridays to support BAHA/Cochlear engagement material preparation. This involved usage of both printers as well as office heating being on throughout the day.



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NHS All Wales Clinical Waste and Municipal Waste Contracts are awarded through an NHS All Wales Tender Process managed by NWSSP Procurement services on behalf of NHS Wales. Our waste and recycling is processed by Veolia. 'Dry Mixed Recycling' (DMR) is collected and separated for recycling by Veolia. We also work with staff to raise awareness and understanding of the importance of waste segregation to ensure we can continue to meet our recycling targets.

### **6.10** Duty of Consultation

WHSSC works on behalf of the seven HBs and within the guidance on changes to NHS services in Wales to effectively engage and consult on the services it commissions as required. For any necessary service change that WHSSC leads, it will work through the all Wales engagement leads group in order to utilise existing and established mechanisms at HB level.

# **6.10.1 Specialist Hearing Implant Device Services**

Following notification from CTMUHB in 2019 that they would no longer be able to provide a Cochlear service from the Princess of Wales in Bridgend, due to workforce and sustainability, an urgent temporary service change was enabled. The Covid19 pandemic delayed the ability to proceed with public engagement/consultation during 2019-2021.

Agreement was reached through Health Boards during September 2022, for a period of targeted engagement with regard future provision of both Cochlear and Bone Conduction Hearing Implants (BCHI). Early discussions were held with Community Health Councils to agree the approach at the outset. The proposed scope for the targeted engagement was to talk with people across South East Wales, South West Wales and South Powys on the ideas we have about how specialist hearing implant device services could be provided in the future. A total of 952 patients were contacted via their local clinical teams and the Consultation period run between 4 January 2023 and 14 February 2023. There were a total of 201 responses received. The findings are currently in the process of being collated and the outcome will be reported to the May 2023 JC meeting.

### 6.11 Ministerial Directions 2022-2023

Ministerial Directions issued by the Welsh Government during 2022-2023 have been considered and where appropriate implemented. Whilst Ministerial Directions are received by NHS Wales organisations, these are not always applicable to WHSSC. Ministerial Directions issued throughout the year are listed on the Welsh Government website.

Welsh Health Circulars (WHCs) issued by Welsh Government are logged by the Corporate Governance Function. WHSSC has acted upon, and responded to all Welsh Health Circulars (WHC) issued during 2022-23 which were applicable to WHSSC. A list of WHC's issued by Welsh Government during 2022-23 is available here.

During 2022-2023, the following Welsh Health Circulars (WHCs) were relevant to WHSSC:

WHC
WHC/2022/008 – New records management code of practice for health and care 2022
WHC/2022/012 – Donation and transplantation plan 2022 to 2026.
WHC/2022/013 – Health boards, special health authorities and trusts financial monitoring guidance 2022 to 2023
WHC/2022/017 –Wales rare disease action plan 2022 to 2026
<u>WHC/2022/020 – Never events: policy and incident list July 2022</u>
WHC/2022/032 – Further extending the use of Blueteq in secondary care
WHC/2022/034 – Health Board Allocations for 2023 to 2024
WHC/2023/06 – Commencement of the Health and Social Care (Quality and Engagement) (wales) Act 2020

# **6.12 Data Security & Information Governance**

The Committee Secretary is the Lead Officer in relation to Information Governance for WHSSC. An agreement has been made that the Medical Director of CTMUHB, as host organisation, will act as Caldicott Guardian for WHSSC. The Caldicott Guardian, is responsible for the protection of patient information. Guidance and support on Information Governance issues is obtained from the IG team at CTMUHB.

The Committee Secretary and the Head of Corporate Governance are members of the CTMUHB Information Governance Group. WHSSC has completed the mandatory Information Governance toolkit annual assessment and this will help inform an action plan with identified priorities for 2023-2024.

There were no WHSSC specific incidents relating to data security that required reporting to the Information Commissioner's Office (ICO) during 2022-2023.

# **6.13 UK Corporate Governance Code**

Whilst there is no requirement to comply with all elements of the Corporate Governance Code for Central Government Departments, the Welsh Health Specialised Services Team (WHSST) considers that it is complying with the main principles of the Code where applicable, through operating within the scope of the governance arrangements for CTMUHB. The WHSST remains satisfied that it

remains compliant with the main principles of the Code, is following the spirit of the Code to good effect and is conducting its business openly and in line with the Code. This has been informed by the Audit Wales "WHSSC Committee Governance Arrangements" Report. There were no reported/identified departures from the Code during the year.

#### 6.14 Counter Fraud

The Counter Fraud Plan was designed to reduce the risk of fraud by reviewing those aspects of WHSSC business that have a residual fraud risk. During the year, the CTMUHB Audit & Risk Committee received regular Local Counter Fraud Progress Reports. These provided a summary of the work that had been undertaken by the Local Counter Fraud Services Team to deliver the Counter Fraud Plan.

# 6.15 Modern Slavery Act 205 – Transparency in Supply Chains

The Welsh Government's Code of Practice: Ethical Employment in Supply Chains was introduced to highlight the need, at every stage of the supply chain, to ensure good employment practices exist for all employees, both in the United Kingdom and overseas.

WHSSC adopts and complies with all CTMUHB procurement processes that embed the principles and requirements of the Code and the Modern Slavery Act 2015. WHSSC is committed to playing its role as a public sector employer, to eradicate unlawful and unethical employment practices, such as:

- Modern Slavery and Human right abuses,
- The operation of Blacklist / prohibited lists,
- False self-employment,
- Unfair use of umbrella schemes and zero hours contracts; and
- Paying the Living Wage.

During 2022 - 2023 WHSSC continued to take the following actions to deliveron the Code's commitments:

- It paid all staff above the minimum living rate (which is at Agenda For Change Band 2),
- It complies with the Raising Concerns (Whistleblowing) Policy, which
  provides the workforce with a fair transparent process, to empower and
  enable them to raise suspicions of any form of malpractice, by either out
  staff or suppliers / contractors working on our premises,
- It has a target in place to pay our suppliers within 30 days of receipt of a valid invoice,
- It does not engage or employ staff or work on Zero Hours Contracts,
- It follows a robust Recruitment and Selection Police and Procedure, which ensure a fair and transparent process as prescribed by its host CTMUHB,
- WHSSC defers the CTMUHB Equality and Diversity Policy, which ensures that no potential applicant, employee or worker engaged by CTMUHB/WHSSC is in anyway unduly disadvantaged, in terms of pay,

- employment rights, employment, training and development of career opportunities,
- Use of the Transparency in Supply Chains (TISC) report Modern Slavery Act (2015) compliance tracker through contracts procured and NWSSP Procurement Services on the CTMUHB's behalf.

#### 6.16 NHS Pension Scheme

As an employer with staff entitled to membership of the NHS Pension Scheme, control measures are in place to ensure all employer obligations contained within the Scheme regulations are complied with. This includes ensuring that deductions from salary, employer's contributions and payments in to the Scheme are in accordance with the Scheme rules, and that member Pension Scheme records are accurately updated in accordance with the timescales detailed in the Regulations.

#### 7.0 REVIEW OF EFFECTIVENESS

As Managing Director for Specialised and Tertiary Services Commissioning, NHS Wales, I have responsibility for reviewing the effectiveness of the system of internal control. My review of the system of internal control is informed by the work of the internal auditors, and the executive officers within the organisation who have responsibility for the development and maintenance of the internal control framework, and comments made by external auditors and other reports.

Despite this not being a statutory obligation for WHSSC, it is a principle of good governance and best practice that all Wales NHS organisations should undertake a formal and rigorous annual evaluation of their own performance and that of their committees in accordance with the Standing Orders.

The IGC plays a central role in the scrutiny of a number of key governance mechanisms for which it provides assurances to the Joint Committee. The IGC is responsible for agreeing the organisation wide approach to the annual effectiveness self-assessment and for monitoring progress against any identified actions.

For the 2021-2022 assessment, a survey was issued via Microsoft Forms to enable an efficient yet effective reflection on committee effectiveness, which offers a consistent approach for all committees. The 2021-2022 self-assessment survey was issued to all members on 30 March 2022.

The survey questions were derived from best practice guidance, including the NHS Audit Handbook, and adhered to the following principles:

• the need for sub-committees to strengthen their governance arrangements and support the JC in the achievement of the strategic objectives,

- the requirement for a committee structure that strengthens the role of the JC in strategic decision making and supports the role of Independent Members in challenging executive management actions,
- maximising the value of the input from Independent Members, given their limited time commitment, and
- supporting the JC in fulfilling its role, given the nature and magnitude of the WHSSC agenda.

A number of standard questions were included in the survey questionnaires to all committee members. In addition, the Chairs of each sub-committee meeting were also invited to consider some bespoke and individual questions for their sub-committee members to consider.

Overall, the surveys received a positive response, and the findings and the feedback contributed to the development of a Joint Committee Development plan, which mapped out the development activities for the Joint Committee and its sub committees. A copy of all the development activities that have taken place during 2022-2023 can be found at **Appendix 3**.

For the 2022-2023 assessment, a decision was taken to continue with the use of a Microsoft Forms questionnaire but a blended approach was developed that encourages more narrative. The Committee Effectiveness Questionnaires were circulated on 6 April 2023.

In order to obtain a broad view of the Committee's effectiveness, it is important to consider the additional mechanisms and tools, which are used in order to provide evidence that WHSSC's systems of internal control are working effectively. By using the tools outlined in **table 4** below to map the various sources of assurance issues, gaps in controls and/or gaps in assurance can be identified:

Table 4 - Tools to Review Effectiveness

Tool	Scope	Assurance Reporting
Corporate Risk Assurance Framework (CRAF)	This is an essential component of WHSSC's internal control system and is used as a systematic and	The CRAF is presented to each QPSC, IGC and ARC meeting and is presented to the Joint Committee every 6 months.
	structured method of recording all risks (operational, financial and strategic) that threaten the achievement of	The operating framework for the CRAF is outlined in the Risk Management Strategy.

Tool	Scope	Assurance Reporting
	WHSSCs objectives. This forms an integral part of dayto-day practices and culture, utilising a single co-ordinated approach to the identification, assessment and management of all types of risk.	
Internal audit	Look at areas related to corporate governance, risk management and internal control.	The WHSSC Audit tracker outlines audits undertaken and progress being made against recommendations, and is presented to each ARC and IGC meeting.
External Audit	Look at areas related to corporate governance, risk management and internal control.	The Audit Wales Report on Committee Governance Arrangements was presented at JC, IGC and ARC meetings throughout 2022-2023. The tracking report was included on HB Audit Committee agendas to ensure that all NHS bodies were able to maintain a line of sight on the progress being made, noting WHSSC's status as a Joint Committee of each HB in Wales.
Internal Policies	Policies and procedures designed to give management a reasonable assurance that the company achieves its objectives	A report on operational policies is presented to the QPSC and IGC routinely for assurance.  The WHSSC internal policy group oversee the management of all policies and report to CDGB. A policy update is also shared with QPSC and MG.

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Tool	Scope	Assurance Reporting
Regulatory and Legal	Compliance with regulatory and legislative frameworks.	Routine assurance reports to JC and sub committees and the Annual Governance Statement (AGS).
Stakeholder feedback	Receiving feedback from people (named or anonymous), whose views are considered helpful and relevant.	WHSSC obtain stakeholder feedback through formal consultation processes and through regular dialogue with the JC, sub committees, through attending peer group meetings and 1 to 1 meetings.
Joint Assurance Framework (JAF)	Brings together in one place all of the relevant information on the risks to the achievement of strategic objectives. Known as a Board Assurance Framework (BAF) in HB's.	WHSSC have made a commitment to introducing a JAF in the risk management strategy; however, this has not yet been developed.

<sup>\*</sup>Note this list is not exhaustive

#### 7.1 Internal Audit

Internal audit provide me as Managing Director and the Joint Committee, through the CTMUHB Audit & Risk Committee, with a flow of assurance on the system of internal control. I have commissioned a programme of audit work that has been delivered in accordance with public sector internal audit standards by the NHS Wales Shared Services Partnership (NWSSP). The scope of this work is agreed with the CTMUHB Audit & Risk Committee and is focussed on significant risk areas and local improvement priorities.

The overall opinion by the Head of Internal Audit on governance, risk management and control is a function of this risk based audit programme and contributes to the picture of assurance available to the Joint Committee in reviewing effectiveness and supporting our drive for continuous improvement.

The CTMUHB Audit & Risk Committee regularly reviews and considers the work and findings of the internal audit team. The Director of Audit and Assurance and the relevant Heads of Internal Audit have attended each meeting to discuss their

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work and present their findings. The CTMUHB Audit & Risk Committee is satisfied with the liaison and coordination between the external and internal auditors.

The following reviews were completed by Internal Audit during 2022-2023:

Audit Theme	Assessment Rating
Risk Management	Reasonable
	Assurance
Neurosciences and Long Term Conditions	Substantial
Programme Team	Assurance
Quality Assurance Reporting	Substantial
	Assurance

The internal audit programme was impacted by the need to defer two audits into 2023-2024 to focus more on strategy implementation instead of the normal commissioning team reviews.

The following topics are planned for the 2023-2024 internal audit timetable:

Audit Theme	Date	
Neurosciences and Long Term	Quarter 1 (April – June	
Conditions Programme Team	2023)	
Welsh Kidney Network	Quarter 2	
(Deferred from 2022-2023)	(July - September 2023)	
Mental Health	Quarter 3/4	
(Deferred from 2022-2023)	(TBC	
	October -December	
	2023 or January to	
	March 2024.	

For internal audit, the CTMUHB Audit & Risk Committee (ARC) monitored implementation of management actions agreed in response to reported weaknesses. Reports were generated that enabled the ARC to understand operational and financial risks.

# 7.2 External Audit

The Auditor General for Wales is CTMUHB's statutory external auditor and the Audit Wales undertakes audits on his behalf. Audit Wales scrutinises the Health Board's financial systems and processes, performance management, key risk areas and the Internal Audit function. This includes the governance and finances of WHSSC.

As an organisation hosted by CTMUHB, the work of external audit is monitored by the CTMUHB Audit & Risk Committee through regular progress reports. The recommendations made are relevant and helpful in our overall assurance and

governance arrangements and our work on minimising risk. There are clear and open relationships with officers and the reports produced are comprehensive and well presented.

In addition to WHSSC matters, the CTMUHB Audit & Risk Committee has been kept appraised by its external auditors of developments across NHS Wales and elsewhere in the public service. These discussions have been helpful in extending the Audit & Risk Committee's awareness of the wider context of our work and specific updates have been provided

In May 2021, Audit Wales published the "<u>Committee Governance Arrangements</u> <u>at WHSSC</u>" which outlined the findings of the review undertaken between March and June 2020, and in July 2021 (as a result of the COVID-19 pandemic, aspects of the review were paused, and re-commenced in July).

The scope of the work included interviews with officers and independent members at WHSSC, observations from attending Joint Committee and sub-committee meetings, feedback from questionnaires issued to HB Chief Executive Officers and Chairs and a review of corporate documents.

The report outlined four recommendations for WHSSC and the three recommendations for Welsh Government as outlined below:

#### **Audit Wales Recommendations**

# **WHSSC**

**R1** Increase the focus on quality at the Joint Committee. This should ensure effective focus and discussion on the pace of improvement for those services in escalation and driving quality and outcome improvements for patients.

**R2** Implement clear programme management arrangements for the introduction of new commissioned services. This should include clear and explicit milestones which are set from concept through to completion (i.e. early in the development through to post implementation benefits analysis). Progress reporting against those milestones should then form part of reporting into the Joint Committee.

**R3** In the short to medium term, the impact of COVID-19 presents a number of challenges. WHSSC should undertake a review and report analysis on:

- a. the backlog of waits for specialised services, how these will be managed whilst reducing patient harm.
- b. potential impact and cost of managing hidden demand. That being patients that did not present to primary or secondary care during the pandemic, with conditions potentially worsening.

The financial consequences of services that were commissioned and underdelivered as a result of COVID-19, including the under-delivery of services commissioned from England. This should be used to inform contract negotiation.

**R4** The current specialised services strategy was approved in 2012. WHSSC should develop and approve a new strategy during 2021. This should:

- a. embrace new therapeutic and technological innovations, drive value, consider best practice commissioning models in place elsewhere, and drive a short, medium, and long-term approach for post pandemic recovery.
- b. be informed by a review of the extent of the wider services already commissioned by WHSSC, by developing a value-based service assessment to better inform commissioning intent and options for driving value and where necessary decommissioning.

The review should assess services:

- which do not demonstrate clinical efficacy or patient outcome (stop);
- which should no longer be considered specialised and therefore could transfer to become core services of HBs (transfer);
- where alternative interventions provide better outcome for the investment (change); currently commissioned, which should continue.

Progress against the WHSSC actions outlined within the management response are monitored through the Integrated Governance Committee (IGC) and the Joint Committee (JC).

### **Welsh Government**

**R5** Review the options to recruit and retain WHSSC independent members. This should include considering measures to expand the range of NHS bodies that WHSSC members can be drawn from, and remuneration for undertaking the role.

**R6** This is linked to Recommendation 2 made to WHSSC in this report. When new regional or sub-regional specialised services are planned which are not the sole responsibility of WHSSC, ensure that effective multi- partner programme management arrangements are in place from concept through to completion (i.e. early in the development through to post-implementation benefits analysis).

**R7** A Healthier Wales included a commitment to review the WHSSC arrangements along with other national hosted and specialist advisory functions. COVID-19 has contributed to delays in taking forward that action. It is recommended that the Welsh Government set a revised timescale for the action and use the findings of this report to inform any further work looking at governance and accountability arrangements for commissioning specialised services as part of a wider consolidation of current national activity.

Progress against the WG management responses is monitored through discussions between the Chair, the WHSSC Managing Director and the Director General Health & Social Services/ NHS Wales Chief Executive.

Progress against each recommendation is provided via an Audit Tracker document which was presented to the Joint Committee and the CTMUHB ARC during 2022-2023. The Joint Committee received and approved the tracker

document on <u>10 January 2023</u>. The ongoing scrutiny being undertaken through the IGC was noted.

A further progress report was provided to the IGC Committee meeting on 13 April 2023 with further positive progress noted.

As at the time of reporting, the majority of actions have been completed and there are only two areas of partial compliance relating to:

- the WHSSC Specialised Services Strategy,
- the appointment of an Assistant Medical Director (AMD) for Public Health.

Both of these outstanding actions are on course to be completed by June 2023.

The report outlined three recommendations for Welsh Government (WG) and progress against the WG management responses is monitored through discussions between the Chair, the WHSSC Managing Director and the Director General Health & Social Services/ NHS Wales Chief executive.

A progress report was sent to Board Secretaries in HBs for inclusion on HB Audit Committee agendas in February/March 2022 to ensure that all NHS bodies were able to maintain a line of sight on the progress being made, noting WHSSC's status as a Joint Committee of each HB in Wales.

Following closure of all remaining recommendations, a final report will be sent to the JC for assurance and then onto the Board Secretaries in HBs for inclusion on HB Audit Committee agendas before the Audit Wales Recommendations into Committee Governance Arrangements at WHSSC can be formally closed.

# 8.0 CONCLUSION

As indicated throughout this statement the recovery agenda and the extreme financial pressures and service challenges facing NHS Wales has had a significant impact on the organisation, the wider NHS and society as a whole. It has required a dynamic response that has presented a number of opportunities and risks. WHSSC has sought to support commissioned services to recover and return to a position of pre-COVID activity, with variable achievement across our providers. As a result, Performance Management arrangements will continue to be a key priority in 2023-2024 to ensure that high quality services continue to be commissioned for the Welsh population. I will ensure our Governance Framework considers and responds to this need.

As Managing Director, based on the assurance process outlined above, I have reviewed the relevant evidence and assurances in respect of internal control. I can confirm that the WHSST are alert to their accountabilities in respect of internal control and that that no significant internal control or governance issues have been identified.

In summary, my review confirms that the WHSCC has sound systems of internal control in place to support the delivery of policy aims and objectives and that there are no significant internal control issues to report for 2022-2023.

Melho

**Dr Sian Lewis** 

Managing Director of Specialised and Tertiary Services Commissioning, NHS Wales

Date: 31 March 2023

Appendix 1

<u>Table 1 - of Membership and Attendance for the Joint Committee 2022 - 2023</u>

Name	Role	Organisation	Attendance at Meetings 2022-2023		
	Non Officer Members				
Kate Eden	Chair	Welsh Health Specialised Services Committee	8/8		
Ceri Phillips	Member	Vice Chair, Cardiff and Vale UHB	6/8		
Ian Wells	Member (until 30 November 2023)	Independent Member, Cwm Taf Morgannwg UHB	4/4		
Steve Spill	Member (from 30 November 2023)	Independent Member, Cwm Taf Morgannwg UHB	3/4		
Chantal Patel	Member (from 30 November 2023)	Independent Member, Cwm Taf Morgannwg UHB	3/4		
	Chief Exe	cutive Members*			
Mark Hackett	Member	Chief Executive, Swansea Bay UHB	7/8		
Glyn Jones	Member (until 1 September 2022)	Interim Chief Executive, Aneurin Bevan UHB	3/3		
Paul Mears	Member	Chief Executive, Cwm Taf Morgannwg UHB	7/8		
Steve Moore	Member	Chief Executive, Hywel Dda UHB	7/8		
Suzanne Rankin	Member	Chief Executive, Cardiff & Vale UHB	7/8		
Carol Shillabeer	Member	Chief Executive, Powys Teaching HB	8/8		
Jo Whitehead	Member (until January 2023)	Chief Executive, Betsi Cadwaladr UHB	2/3		
Gill Harris	Member (from 17 January 2023)	Interim Chief Executive, Betsi Cadwaladr UHB	5/5		
Nicola Prygodzicz	Member (from 1 September 2022)	Chief Executive Officer, Aneurin Bevan UHB	4/5		
Welsh Health Specialised Services Officer Members					
Carole Bell	Officer Member	Director of Nursing and Quality Assurance	7/8		
Stuart Davies	Officer Member	Director of Finance	8/8		
Iolo Doull	Officer Member	Medical Director	7/8		
Sian Lewis	Officer Member	Managing Director	8/8		
Karen Preece	Officer (until 6 September)	Director of Planning	3/3		
Nicola Johnson **	Officer (from 7 September 2022)	Director of Planning	5/5		
Jacqui Evans **	Officer	Committee Secretary	8/8		
	Associate Members				
Tracey Cooper	Associate Member	Chief Executive, Public Health Wales NHS Trust	0/8		

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Name	Role	Organisation	Attendance at Meetings 2022-2023	
Steve Ham	Associate Member	Chief Executive, Velindre NHS Trust	1/8***	
Jason Killens	Associate Member	Chief Executive, Welsh Ambulance Service NHS Trust	0/8	
Independent Chair WKN				
Ian Phillips	Member	Independent Member, Powys Teaching HB	6/8	

<sup>\*</sup> In person or represented by a nominee in accordance with the Joint Committee SOs.

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<sup>\*\*</sup> As per the Standing Orders the Director of Planning and Committee Secretary are not voting members of the JC but are both regular attendees.

<sup>\*\*\*</sup> Part meeting only

# **Appendix 2**

# <u>Table 2 - Dates of Joint Committee Meetings 2022-2023</u>

The following table outlines the months during which meetings of the Joint Committee and joint sub-committee meetings were held during 2022-2023.

	2022				2023							
	Apr	May	Jun	July	Aug	Sept	Oct	Nov	Dec	Jan	Feb	Mar
Joint Committee		10		12		06		08		17		14
Joint Committee (extraordinary)										10	13	
Integrated Governance	19		07		09		11				14	
All Wales IPFR Panel	07* 21*	05* 23	08 16	07 21*	04 18	01 15	06 20*	03 17	15**	05* 19	02 16	02 16
Management Group	28	26	23	28	25	22	27	24	15	26	23	23
Quality & Patient Safety			07		09		25			24		21
Welsh Renal Clinical Network	08		06				06	23			02	

<sup>\*</sup>Inquorate - All meetings were quorate with the exception of the IPFR panel. During these times, the Chair's Action arrangement outlined in the Terms of Reference (ToR) was used to ensure business continuity for urgent cases.

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<sup>\*\*</sup> Cancelled due to Strike Action

**IPFR Panel Meetings Jan -May 2022** - Due to ongoing pressures within HBs relating to the pandemic, and in particular staff absence levels, and as result of a letter received from Mrs Judith Paget, Chief Executive Officer of NHS Wales suggesting NHS bodies step down any non-essential meetings, the Individual Patient Funding Request (IPFR) Panel returned to the process previously adopted during the start of the pandemic to ensure business continuity until the end of May 2022.

The full IPFR Panel was stood down until May 2022, and operated via the Chair's Action arrangement outlined in the Terms of Reference (ToR). This process was strengthened by including the attendance of two WHSSC Clinical Directors and a lay member representative. The situation was monitored on a monthly basis and due to the on-going work pressures related to the NHS recovery following Covid-19, full IPFR meeting resumed in May 2022 when attendance from Clinical staff could be secured. There remained some meetings where quoracy was not achieved and on these few occasions, the full IPFR meeting was stood down and a Chairs Action Panel was convened to avoid any delays in decision making.

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# **APPENDIX 3**

# **Joint Committee Development Plan 2022-2023**

Meeting Date	Topic	Plan for Delivery and Evaluation
<b>Joint Committee</b>		•
10 May 2022	Genomics- Sian Morgan Early presentation at a normal JC May/June/July on good news developments from genomics focussing on Non-invasive pre-natal testing and DPYD testing (for avoiding chemo risk in colo-rectal patients).	<ul> <li>Through the IGC</li> <li>Annual Committee Effectiveness survey 2022-2023</li> </ul>
12 July 2022	Workshop - Recovery Trajectories across NHS Wales  JC meeting 10 May 2022 requested a specific workshop on recovery.	<ul> <li>Through the IGC</li> <li>Annual Committee Effectiveness survey 2022-2023</li> </ul>
6 September 2022	ATMP's/Genomics Delivery Plan for Wales Strategic piece covering the next phases of expansion/development in ATMPs and genomics delivery in Wales.  Major Trauma Presentation – to update JC members on progress since the launch of the service in September 2020.	<ul> <li>Through the IGC</li> <li>Annual Committee Effectiveness survey 2022-2023</li> </ul>
	<b>Specialised Services Strategy Presentation</b> – to inform JC of the planned development of a ten year	

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Meeting Date	Topic	Plan for Delivery and Evaluation
	strategy for specialised services for the residents of Wales, and to describe the proposed approach to communication and engagement with key stakeholders to support its development.	
8 November 2022	2023 – 2026 ICP Presentation – An overview of the ICP for the next year was provided. The emerging financial plan was shared with members. Arrangements were in progress for all business cases to be scrutinised prior to going through WHSSC's governance processes in line with the financial commitments in its plan.  Recovery Update (incl. Progress with Paediatric Surgery) Members received a presentation providing an update on recovery trajectories since the workshops held with the Joint Committee on the 12 July and 6 September 2022. A focus on Paediatric Surgery was requested.	Through the IGC     Annual Committee Effectiveness survey 2022-2023
10 January 2023	ICP Workshop – to discuss financial scenarios	<ul><li>Through the IGC</li><li>Annual Committee Effectiveness survey 2022-2023</li></ul>
17 January 2023	ICP Presentation – Updated Financial Position Including more detail around the risks and scenarios	<ul> <li>Through the IGC</li> <li>Annual Committee Effectiveness survey 2022-2023</li> </ul>

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Meeting Date	Topic	Plan for Delivery and Evaluation					
14 March 2023	Governance System and Process – WHSSC & HB Shared Pathway Saving Target						
<b>Quality &amp; Patient</b>	Quality & Patient Safety Committee/Integrated Governance Committee						
7 June 2022	Quality Newsletter  Service Innovation & Improvement Update	<ul><li>Through the IGC</li><li>Annual Committee Effectiveness survey 2022-2023</li></ul>					
9 August 2022	Mother & Baby Serious Untoward Incident Feedback  Ty Llidiard Update	<ul> <li>Through the IGC</li> <li>Annual Committee Effectiveness survey 2022-2023</li> </ul>					
26 September 2022	Annual QPSC Development Day	Feedback following the event					
25 October 2022	Neonatal Intensive Care Unit Experiences – patient story	<ul><li>Through the IGC</li><li>Annual Committee Effectiveness survey 2022-2023</li></ul>					
24 January 2023	Mental Health Deep Dive	<ul> <li>Through the IGC</li> <li>Annual Committee Effectiveness survey 2022-2023</li> </ul>					
18 April 2023	Major Trauma Presentation	<ul><li>Through the IGC</li><li>Annual Committee Effectiveness survey 2022-2023</li></ul>					
Individual Patient Funding Request Panel (IPFR)							
17 December 2021	Barrister briefing for IPFR members following the Judicial Review						
2 December 2022	Stakeholder Engagement with KC David Lock on IPFR Policy Changes and WHSSC ToR review						
28 February 2023	Annual IPFR Training and Development Session						

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<b>Meeting Date</b>	Topic	Plan for Delivery and Evaluation
Welsh Kidney Net		
27 April 2022	Academi Wales Workshop	<ul> <li>WKN governance review</li> </ul>
<b>Management Grou</b>	ир	
28 April 2022	Presentation National Collaborative Commissioning Unit Secure Services Report	<ul><li>Through the IGC</li><li>Annual Committee Effectiveness survey 2022-2023</li></ul>
23 June	Inductions for New Members	<ul><li>Through the IGC</li><li>Annual Committee Effectiveness survey 2022-2023</li></ul>
28 July 2022	Overview of Schemes received by the Clinical Impact Assessment Group (CIAG) for the 2023-2024 Integrated Commissioning Plan (ICP)	<ul> <li>Through the IGC</li> <li>Annual Committee Effectiveness survey 2022-2023</li> </ul>
25 August 2022	Major Trauma Presentation Paediatric Services Deep Dive	<ul><li>Through the IGC</li><li>Annual Committee Effectiveness survey 2022-2023</li></ul>
22 September 2022	Prioritisation Panel – Update  Plastic Surgery Commissioning Arrangements Workshop	<ul> <li>Through the IGC</li> <li>Annual Committee Effectiveness survey 2022-2023</li> </ul>
24 November 2022	Recommissioning for Value Workshop	<ul><li>Through the IGC</li><li>Annual Committee Effectiveness survey 2022-2023</li></ul>
15 December 2022	ICP Update  Congenital Heart Disease National Standards Self-Assessment (Welsh Level 3 Centres)	<ul> <li>Through the IGC</li> <li>Annual Committee Effectiveness survey 2022-2023</li> </ul>

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Meeting Date	Topic	Plan for Delivery and Evaluation
	Single Commissioner Model Presentation	
26 January 2023	Haematology workshop	<ul><li>Through the IGC</li><li>Annual Committee Effectiveness survey 2022-2023</li></ul>
23 March 2023	Specialised Services Strategy	<ul><li>Through the IGC</li><li>Annual Committee Effectiveness survey 2022-2023</li></ul>
CDGB		
23 May 2022	Improvement Cymru – Quality workshop	<ul><li>Through the IGC</li><li>Annual Committee Effectiveness survey 2022-2023</li></ul>
3 October 2022	Briefing from Welsh Government (WG) on the Health & Social Care (Quality & Engagement) (Wales) Act 2022 with a specific focus on the consultation process for the duty of candour	<ul> <li>Through the IGC</li> <li>Annual Committee Effectiveness survey 2022-2023</li> </ul>
29 November 2022	Compassionate Leadership, Kings Fund, Michael West	<ul> <li>Through the IGC</li> <li>Annual Committee Effectiveness survey 2022-2023</li> </ul>

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