2023-05-16 JC (Public)

Tue 16 May 2023, 09:30 - 12:20

Agenda

09:30 - 09:35
5 min

1. PRELIMINARY MATTERS

0.0 JC Public Agenda 16 May 2023.pdf (2 pages)

1.1. Welcome and Introductions

Oral *Chair*

1.2. Apologies for Absence

Oral *Chair*

1.3. Declarations of Interest

Oral *Chair*

1.4. Minutes of the Meeting held on 14 March 2023 and Matters Arising

Att. *Chair*

1.4 Unconfirmed JC (Public) Minutes 14 March 2023 V6.pdf (18 pages)

1.5. Action Log

Att. *Chair*

1.5 JC Action Log 16 May 23.pdf (5 pages)

09:35 - 10:35
60 min

2. PRESENTATION

2.1. WHSSC Specialised Services Strategy

Att. and To Follow *Director of Planning*

2.1 Specialised Services Commissioning Strategy.pdf (6 pages)
2.1.1 Appendix 1 - WHSSC Specialised Services Commissioning Strategy v22.pdf (32 pages)

2.2. WHSSC & HB Shared Pathway Saving Target - Milestones on Governance System and Process

To Follow *Director of Planning*

10:35 - 11:40
65 min

3. ITEMS FOR CONSIDERATION AND / OR DECISION

3.1. Chair's Report

Att. *Chair*

3.1 Chair's Report JC 16 May 2023.pdf (4 pages)
3.1.1 Appendix 1 - Final Letter Chairs action Extension of WHSSC IM 10 May 2023.pdf (2 pages)

3.2. Managing Director's Report

Att. *Managing Director*

- 3.2 Managing Director's Report.pdf (4 pages)
- 3.2.1 Appendix 1 - Letter to WHSSC re single commissioning model.pdf (1 pages)
- 3.2.2 Appendix 2 - Commissioning of SNS.pdf (2 pages)
- 3.2.2a Appendix 2a - Sacral Nerve Stimulation v0.2 240123.pdf (5 pages)

3.3. Review of Specialised Commissioning in Haematology: Acute Myeloid Leukaemia (AML), Acute Lymphoblastic Leukaemia (ALL) and High Risk Myelodysplasia

Att. *Director of Planning*

- 3.3 Review of Specialised Commissioning in Haematology AML ALL and HRM.pdf (11 pages)
- 3.3.1 Appendix 1 - Full Report Findings and Proposals for AML ALLHRM.pdf (17 pages)

3.4. Review of Specialised Commissioning in Haematology: Allogeneic Haematopoietic Stem Cell Transplantation, Salvage Therapy in Non-Hodgkin's Lymphoma and Secondary Immunodeficiency

Att. *Director of Planning*

- 3.4 Review of Specialised Commissioning in Haematology BMT NHL.pdf (11 pages)
- 3.4.1 Appendix 1 - Post 100 day BMT salvage therapy.pdf (16 pages)

3.5. Review of Specialised Commissioning in Haematology: Thrombotic Thrombocytopenic Purpura

Att. *Director of Planning*

3.6. Cochlear and Bone Conduction Hearing Implant (BCHI) Engagement & Next Steps

Att. *Director of Planning*

3.7. Performance Management Framework

Att. *Director of Planning*

3.8. Development of the Integrated Commissioning Plan 2024-2027

Att. *Director of Planning*

3.9. Annual Governance Statement 2023-2023

Att. *Committee Secretary*

3.10. Sub Committee Annual Reports

Att. *Committee Secretary*

3.11. Sub Committee Terms of Reference

Att. *Committee Secretary*

11:40 - 12:15
35 min

4. ROUTINE REPORTS AND ITEMS FOR INFORMATION

4.1. Performance and Activity Report Month 11 2022-2023

Att. *Director of Finance*

4.2. Financial Performance Report Month 12 2022-2023

Att. *Director of Finance*

4.3. South Wales Trauma Network Delivery Assurance Group (Quarter 3 Report)

Att. *Director of Planning*

4.4. Corporate Governance Report

Att. *Committee Secretary*

4.5. Reports from the Joint Committee Sub-Committees

4.5.1. Audit and Risk Committee (ARC) Assurance Report

Att. *Committee Secretary*

4.5.2. Management Group Briefings

Att. *Managing Director*

4.5.3. Individual Patient Funding Request (IPFR) Panel

Att. *Managing Director*

4.5.4. Integrated Governance Committee (IGC)

Att. *Chair*

4.5.5. Quality & Patient Safety Committee (QPSC)

Att. *Sub Committee Chair*

4.5.6. Welsh Kidney Network (WKN)

Att. *Sub Committee Chair*

12:15 - 12:20
5 min

5. CONCLUDING BUSINESS

5.1. Any Other Business

Oral *Chair*

5.2. Date of Next Meeting

Oral *Chair*

18 July 2023 at 13.30hrs

5.3. In Committee Resolution

Oral *Chair*

The Joint Committee is recommended to make the following resolution: “That representatives of the press and other members of the public be excluded from the remainder of this meeting having regard to the confidential nature of the business to be transacted, publicity on which would be prejudicial to the public interest” (Section 1 (2) Public Bodies (Admission to Meetings) Act 1960)”.

WHSSC Joint Committee Meeting held in public
Tuesday 16 May 2023 at 09:30 hrs

Microsoft Teams

ITEM		LEAD	PAPER / ORAL	TIME
1.0	**PRELIMINARY MATTERS**			
1.1	Welcome and Introductions	Chair	Oral	09:30 - 09:35
1.2	Apologies for Absence	Chair	Oral	
1.3	Declarations of Interest	Chair	Oral	
1.4	Minutes of the Meeting held on 14 March 2023 and Matters Arising	Chair	Att.	
1.5	Action Log	Chair	Att.	
2.0	**PRESENTATION**			
2.1	WHSSC Specialised Services Strategy	Director of Planning	Att. and to follow	9:35 - 10:15
2.2	WHSSC & HB Shared Pathway Saving Target – Milestones on Governance System & Process	Director of Planning	To follow	10:15 - 10:35
3.0	**ITEMS FOR CONSIDERATION AND/OR DECISION**			
3.1	Chair's Report	Chair	Att.	10:35 – 10:40
3.2	Managing Director's Report	Managing Director	Att.	10:40 – 10:45
3.3	Review of Specialised Commissioning in Haematology: Acute Myeloid Leukaemia (AML), Acute Lymphoblastic Leukaemia (ALL) and High Risk Myelodysplasia	Director of Planning	Att.	10:45 - 10:50
3.4	Review of Specialised Commissioning in Haematology: Allogeneic Haematopoietic Stem Cell Transplantation, Salvage Therapy in Non-Hodgkin's Lymphoma and Secondary Immunodeficiency	Director of Planning	Att.	10:50 - 10:55
3.5	Review of Specialised Commissioning in Haematology: Thrombotic Thrombocytopenic Purpura	Director of Planning	Att.	10:55 - 11:00
3.6	Cochlear and Bone Conduction Hearing Implant (BCHI) Engagement & Next Steps	Director of Planning	Att.	11:00 - 11:10

ITEM		LEAD	PAPER / ORAL	TIME
3.7	Performance Management Framework	Director of Planning	Att.	11:10 - 11:20
3.8	Development of the Integrated Commissioning Plan 2024-2027	Director of Planning	Att.	11:20 - 11:25
3.9	Annual Governance Statement 2022-2023	Committee Secretary	Att.	11:25 - 11:30
3.10	Sub Committee Annual Reports	Committee Secretary	Att.	11:30 - 11:35
3.11	Sub Committee Terms of Reference	Committee Secretary	Att.	11:35 - 11:40
4.0	**ROUTINE REPORTS AND ITEMS FOR INFORMATION**			
4.1	Performance and Activity Report Month 11 2022-2023	Director of Finance	Att.	11:40 - 11:45
4.2	Financial Performance Report Month 12 2022-2023	Director of Finance	Att.	11:45 - 11:50
4.3	South Wales Trauma Network Delivery Assurance Group (Quarter 3 Report)	Director of Planning	Att.	11:50 - 11:55
4.4	Corporate Governance Report	Committee Secretary	Att.	11:55 - 12:00
4.5	Reports from the Joint Sub-Committees 4.5.1 Audit and Risk Committee (ARC) Assurance Report 4.5.2 Management Group Briefings 4.5.3 Individual Patient Funding Request (IPFR) Panel 4.5.4 Integrated Governance Committee (IGC) 4.5.5 Quality & Patient Safety Committee (QPSC) 4.5.6 Welsh Kidney Network (WKN)	Joint Sub-Committee Chairs	Att.	12.10 - 12.15
5.0	**CONCLUDING BUSINESS**			
5.1	Any Other Business	Chair	Oral	
5.2	Date of Next Meeting (Scheduled) - 18 July 2023 at 13.30hrs	Chair	Oral	
5.3	In Committee Resolution The Joint Committee is recommended to make the following resolution: "That representatives of the press and other members of the public be excluded from the remainder of this meeting having regard to the confidential nature of the business to be transacted, publicity on which would be prejudicial to the public interest" (Section 1 (2) Public Bodies (Admission to Meetings) Act 1960)".	Chair	Oral	12:15 - 12:20

Unconfirmed Minutes of the Meeting of the WHSSC Joint Committee Meeting held In Public on Monday 14 March 2023 via MS Teams

Members

Kate Eden	(KE)	Chair, WHSSC
Stuart Davies	(SD)	Director of Finance, WHSSC
Nicola Johnson	(NJ)	Director of Planning, WHSSC
Sian Lewis	(SL)	Managing Director, WHSSC
Paul Mears	(PM)	Chief Executive Officer, Cwm Taf Morgannwg UHB
Chantal Patel	(ChP)	Independent Member, WHSSC
Ceri Phillips	(CP)	Independent Member, WHSSC
Suzanne Rankin	(SR)	Chief Executive Officer, Cardiff and Vale UHB
Carol Shillabeer	(CS)	Chief Executive Officer, Powys Teaching HB
Steve Spill	(SS)	Independent Member, WHSSC

Deputies:

Rob Holcombe (for Nicola Prygodzicz)	(RH)	Executive Director of Finance, ABUHB
Chris Stockport (for Gill Harris)	(CS)	Executive Director Transformation And Strategic Planning

Apologies:

Carole Bell	(CB)	Director of Nursing & Quality, WHSSC
Iolo Doull	(ID)	Medical Director, WHSSC
Mark Hackett	(MH)	Chief Executive Officer, Swansea Bay UHB
Gill Harris	(GH)	Interim Chief Executive, Betsi Cadwaladr UHB
Carl James	(CJ)	Director of Strategic Transformation, Planning & Digital, Velindre University NHS Trust
Jason Killens	(JK)	Chief Executive, Welsh Ambulance Services NHS Trust
Steve Moore	(SM)	Chief Executive Officer, Hywel Dda UHB
Ian Phillips	(IP)	Independent Chair, Welsh Kidney Network (WKN)
Nicola Prygodzicz	(NP)	Chief Executive Officer, Aneurin Bevan UHB

In Attendance:

Kerry Broadhead	(KB)	Assistant Director of Strategy, SBUHB (for Mark Hackett)
Jacqui Evans	(JE)	Committee Secretary & Associate Director of

		Services
Helen Fardy	(HF)	Associate Medical Director, WHSSC
James Leaves	(JL)	Assistant Director of Finance, WHSSC
Kimberley Meringolo	(KM)	Specialist Services Planning Manager, Women and Children, WHSSC
Ryan O'Dell	(RO)	Assistant Planner, WHSSC
Andrea Richards	(AR)	Senior Project Manager, WHSSC
Dai Roberts	(DR)	Director for Mental Health and Vulnerable, WHSSC Groups, WHSSC
Helen Tyler	(HE)	Head of Corporate Governance, WHSSC
Nick Wood	(NW)	Deputy CEO, NHS Wales Delivery Unit

Minutes:

Gemma Trigg	(GT)	Corporate Governance Officer, WHSSC

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JC23/34	**1.1 Welcome and Introductions** The Chair welcomed Members in Welsh and English and reminded them that meetings will continue to be held virtually via MS Teams. There were no objections raised to the meeting being recorded for administrative purposes. It was noted that a quorum had been achieved.
JC23/35	**1.2 Apologies for Absence** Apologies for absence were noted as above.
JC23/36	**1.3 Declarations of Interest** The Joint Committee (JC) noted the standing declarations and that there were no additional declarations of interest relating to the items for discussion on the agenda.
JC23/37	**1.4 Minutes of the meetings held on 10 January 2023, 17 January 2023, 13 February 2023 and Matters Arising** The minutes of the JC meeting held on 10 January 2023, 17 January 2023 and 13 February 2023 were **received** and **approved** as a true and accurate record of discussions, subject to one minor amendment for all of the minutes to

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	correct the reference to the designated Health Board for the CEO of Powys tHB. There were no matters arising.
JC23/38	**1.5 Action Log** The action log was received, and members noted the progress on the actions and the actions that had been closed.
JC23/39	**2.1 Governance System and Process – WHSSC & HB Shared Pathway Saving Target** The presentation outlining the governance system and process for the Joint Committee to monitor achievement of the 1% WHSSC and HB shared pathway savings target, requested following the approval of the Integrated Commissioning Plan (ICP) 2023-2024 on 13 February 2023 was received. Nicola Johnson (NJ) led the session and members noted that WHSSC had applied a programme management approach to establishing a mechanism to monitor savings and efficiencies. A Project Initiation Document (PID) had been developed including a Programme Board comprising of representatives from each Health Board (HB). The PID had been shared with the Management Group in readiness for a detailed discussion on the 23 March 2023. NJ highlighted the projects already identified and outlined the reporting structure as it is currently. However, members noted that that this was likely to increase as additional projects were identified. Members noted the reporting and escalation detailed within the PID and that savings will be tracked across the pathway. Members noted that updates on progress would be provided as a standing item on the agenda for future Joint Committee meetings. Robert Holcombe (RH) raised a query concerning membership of the Programme Board and highlighted the HBs' responsibility to ensure the work was progressed effectively. He emphasised the importance of having the right members for the project teams which will be set up for each of the saving opportunities.

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	Steve Spill (SS) raised a query around the timetable and milestones and asked if they could be built in. NJ confirmed that the workshop taking place the following week aimed to confirm timetables and will be used to build up the project plan for each scheme. Milestones will be brought back to the Joint Committee meeting on 16 May 2023. **ACTION –** NJ to present milestones on the Governance System and Process – WHSSC & HB Shared Pathway Saving Target to the Joint Committee meeting 16 May 2023. The Chair thanked HB members for their support with this work going forward. The Joint Committee resolved to: • **Note** the presentation.
JC23/40	**3.1 Chair's Report** The Chair's report was received and members **noted**: • The Chair's Action taken on 2 February 2023 to approve urgent patient expenditure for Advanced Medicinal Therapeutic Products (ATMPs) through the Blueteq High Cost Drugs (HCD) software programme, • The request to extend the interim Chair of the Individual Patient Funding Request (IPFR) Panel from 31 March 2023 to 30 September 2023, • That the Minister for Health & Social Services had approved a review of the national commissioning functions, linked to the commitment within 'A Healthier Wales' on a set of actions to strengthen and streamline the NHS landscape in Wales. Members noted that the joint workshop between EASC and WHSSC planned for 14 March 2023 to enable a facilitated discussion on the review had been postponed as the independent facilitator had been taken ill; and • Key meetings attended. Members noted that the Joint EASC/WHSSC workshop on the Welsh Government's (WG's) Review of National Commissioning Functions scheduled to coincide with today's meeting had been postponed and would be rearranged as appropriate. The Joint Committee resolved to:

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	• **Note** the report, • **Ratify** the Chair's action taken on 2 February 2023 to approve expenditure for Advanced Medicinal Therapeutic Products (ATMPs) through the Blueteq High Cost Drugs (HCD) software programme; and **Approve** the recommendation to extend the tenure of the interim Chair of the Individual Patient Funding Request Panel (IPFR) to 30 September 2023 to ensure business continuity.
JC23/41	**3.2 Managing Director's Report** The Managing Director's Report was received and members noted the following updates on: • **Plastic Surgery Outreach Clinics in BCUHB: Update on Quality Concerns** - During the plastic surgery workshop held with the Management Group on 22 September 2022 to consider the future commissioning model for plastic surgery, significant quality concerns were raised by the clinical leads from St Helen's & Knowsley NHS Trust (SHKNT). Since then further concerns were raised during an SLA meeting in February 2023, WHSSC has discussed the issues with colleagues in Welsh Government (WG), and it was agreed that given the issues did not lie directly within the WHSSC commissioning responsibility WG will lead on the escalation process but in liaison with WHSSC. In addition, a Harms Review has been commissioned by BCUHB and the Terms of Reference (ToR) are in the process of being signed off through internal HB processes. SL highlighted the complex governance issues around the commissioning model and the rationale for the escalation to be taken forward through WG. Chris Stockport (CS) confirmed that BCUHB are working with WG to embed improvements and would be happy to provide an update to SL following today's meeting. • **Cochlear Implant and Bone Conduction Hearing Implant Hearing Device Service – Engagement Process Update** – SL informed members that the formal engagement consultation period had closed and the feedback is now being analysed and will be presented to members at the Joint Committee meeting on 16 May 2023; and

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	• **Spinal Operational Delivery Network (ODN)** – Members were advised that the implementation of the Spinal Operational Delivery Network (ODN) had been unfortunately been delayed largely due to the difficulties in appointing an ODN Manager. Those issues have now been resolved and the implementation is continuing as planned. A more detailed update will be presented to the Joint Committee meeting on 16 May 2023. The Joint Committee resolved to: • **Note** the report.
JC23/42	**3.3 Delivering Thrombectomy Capacity in South Wales** The report outlining WHSSC's position on the commissioning of Mechanical Thrombectomy for the population of Wales was received. The Chair reminded members that the report had been presented to the Joint Committee on 8 November 2023 and NJ outlined the work that had been undertaken since then. Members noted that the report updated at the request of the Joint Committee to provide greater emphasis on the networked approach, interdependencies around the network approach and pick up additional elements including the stroke review. Suzanne Rankin (SR) advised that CVUHB had worked jointly with WHSSC and that the Final Business Case had been to the CVUHB Investment Group and there were some minor points of clarification being looked at before it could be submitted. Carol Shillabeer (CS) queried the partnership relationship between CVUHB and Bristol and whether partnering with an experienced service would be beneficial. NJ responded and confirmed that the agreement with Bristol was a commitment to work as a partnership to build up a clinical relationship ensuring there was a safe and sustainable service for patients whilst our underpinning stroke services were being developed. SR advised that CVUHB were working with Bristol to ensure a safe and sustainable solution and that discussions were well underway. The Joint Committee resolved to: • **Note** the report,

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	• **Note** the WHSSC Position Statement on the Commissioning of Mechanical Thrombectomy, • **Note** the associated risks with the current delivery model for Welsh stroke patients requiring access to tertiary Thrombectomy centres; and • **Note** the NHS Wales Health Collaborative (NWHC) proposal to strengthen and improve regional clinical stroke pathways in Wales to support the Mechanical Thrombectomy pathway to ensure that patients receive this time-critical procedure in a timely manner.
JC23/43	**3.4 Eating Disorder In-Patient Provision for Adults** The report outlining the background and medium-term options for procuring adult inpatient eating disorder placements from the independent sector following the end of the service contract between WHSSC and Oxford Health NHS Trust (OHNT) and the current interim arrangements was received. Dai Roberts (DR) presented the report and members noted that the long term solution would be developed as part of Specialised Services Strategy for Mental Health. DR highlighted that the contract would allow WHSSC to commission an additional 8 to 10 beds within the geographical area of Wales and provide stability to the services. CS advised it was important to ensure that patients did not need to travel long distances for treatment, and queried the weighting criteria and asked if there were measures to monitor outcomes. DR responded and advised that it may not be possible to run a unit within Wales due to the specialist skills required and therefore the patient need was balanced against access and proximity together with the skills and expertise of the relevant independent sector provider. DR advised that this was a high risk service for WHSSC because the market was volatile with a limited number of providers and that over the last seven months it had been challenging to access sufficient capacity in the private sector. In the future, it was hoped, the NHS would provide a far more stable environment. Ceri Phillips (CP) advised that there should be a focus on outcomes.

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	Rob Holcombe (RH) advised that it would be reasonable to be flexible in approaching a new service, and suggested that there was a need to look at the history of any organisation to ensure flexibility and enhanced monitoring which could be captured in the service specification. Members noted that DR had experience of setting up the MH facility at Tonna Hospital for SBUHB. Members noted the increased risk that would be carried if an independent sector service could not be procured in the short to medium term. Sian Lewis (SL) assured members that the procurement service specification will clearly outline the expectations for adhering to quality standards and achieving outcomes, that the National Collaborative Commissioning Unit (NCCU) were involved and had extensive experience of monitoring the performance of inpatient eating disorder placements. However, for reasons outlined earlier there were significant challenges in procuring suitable capacity. There was a desire for an NHS Wales solution, however there were financial and capital challenges which would mean this would not happen in the short to medium term. The Chair advised that additional information concerning the weighting criteria would be shared with members outside of the meeting for assurance and that the service was the cornerstone for the Specialised Services for MH. **ACTION:** DR to circulate the proposed weighting criteria to members following the meeting for assurance. The Joint Committee resolved to: • **Note** the information presented within the report to progress tendering and procurement options with the independent sector in line with service need for Welsh patients requiring specialist eating disorder services, • **Note** the medium-term options for adult inpatient eating disorder placements following the end of the contract for eating disorder services between WHSSC and Oxford Health NHS Trust (OHNT) and the current interim arrangements; and

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	• **Receive assurance** that there are robust processes in place to ensure delivery of eating disorder services for adults.
JC23/44	**3.5 Neonatal Transport ODN – Additional Funding Release** The report advising that the Management Group approved the release of £125k for the establishment of the Neonatal Transport Operational Delivery Network (ODN) for Swansea Bay UHB (SBUHB) as the host provider in December 2022, and which sought approval from the Joint Committee for an additional £54k of funding to bridge the shortfall from the original funding request from SBUHB and to allow the implementation of the ODN to proceed was received. NJ presented the report and members noted that the MG had felt that the proposed model did not provide value for money when benchmarked against other networks and networks in NHS England (NHSE). On that basis they approved the benchmarked cost of £125,000 but did not approve the full funding release. Further consideration on next steps and what resources were available was being explored and the funding release was presented to the Collaborative Executive Group (CEG) in January 2023. The CEG recommended that the request be taken to the Joint Committee for approval of the release of £54,000 for SBUHB to operationalise the ODN. CS advised that she recalled historical discussion on the issues and queried whether the progress that had been made within transport services to make improvements could allow these services to align and be more efficient. SL confirmed that work to explore efficiencies and additional ways to improve transport services were being investigated and that WHSSC were working with EASC. Rob Holcombe (RH) queried the process of approval given that MG had refused to release the additional funding. It was noted that the Chief Executives considered this at the Collaborative Group and recommended that the matter be brought back to JC for approval. Members resolved to: • **Note** the report; and

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	• **Approve** the release of an additional £54k funding for the Neonatal Transport ODN to allow the implementation of the Operational Delivery Network (ODN) to proceed.
JC23/45	**3.6 Neonatal Cot Configuration Project** The report outlining the outcomes of the Neonatal Cot Configuration project, the proposed preferred option as recommended by the Project Board and seeking approval for the required long-term next steps was received. NJ outlined the significant work that had been undertaken and the preferred option as recommended by the Project Board. Members noted that the proposed option would not change the designation or patient flow but is about making the service more sustainable in its current form. NJ highlighted the detailed demand and capacity piece of work that had been undertaken with clinical staff. The Project Board explored four options that were developed using British Association of Perinatal Medicine (BAPM) standards. The clinical working group and project board supported option 4. This was presented to the Management Group who supported the proposal to recommend option 4 to the Joint Committee for approval. Members noted that option 4 allowed improvements in staffing to improve outcomes for patients and families and to stabilise funding and contracting arrangements. The investment was included in the ICP this year. NJ requested that the Joint Committee also support a second phase of the review with recommendations likely to come back to the Joint Committee in approximately 2 years. Paul Mears (PM) raised concerns around the phase 2 recommendation due to the impact it potentially would have on the core paediatric services and maternity services. PM asked whether it could be looked at together with the HB Planning Leads rather than a standalone piece of work and to be clear about what was actually achievable in terms of meeting the standards. SR agreed that a strategic discussion around the services in Wales needed to be a regional conversation to see how to do this safely under the current pressures.

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	RH reflected that implementing the BAPM standards would not necessarily give better outcomes and that a mixture of pathways to deploy the work could give the best outcomes. CS reflected on the changes and moves that were recommended following the review 10 years ago and agreed that reaching BAPM standards was a goal to aim for but was very difficult to achieve. Members discussed the need for a broader conversation linked to the interdependencies with maternity services and other core paediatric services, in developing the next steps. The challenges associated with meeting the BAPM standards and the historic work previously undertaken through the South Wales Plan were also discussed. Members noted that the phase 1 element of the work was supported and NJ suggested that phase 1 would provide a good foundation to take forward phase 2. NJ agreed there would be value in taking forward a piece of work with the NHS Wales Directors of Planning Peer Group and would take it there for an initial discussion. Further consideration will then be needed around the scope of the work and the decision making process to implement changes. **ACTION:** NJ to meet with the NHS Wales Directors of Planning peer group for initial discussions on phase 2 of the work for the Neonatal Cot Configuration Project. Members noted that a risk assessment had been undertaken through the Finance Management Sub Group and financial flows and impact on organisations had been mapped for Phase 1. **ACTION:** The risk assessment and Financial flow information to be shared with Joint Committee members. SL confirmed that the request for the funding release was to provide stability to the service and the recommendation to move to phase 2 was a separate question. SL also highlighted that the South Wales Programme was never fully implemented despite being recommended 10 years ago and that the future approach would need to recognise the previous challenges.

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	PM raised the point that HBs were in a different position now from the history of when the South Wales Programme was developed and partner relationships across organisations and key stakeholders had improved so would be in a better position to work toward a joint plan at a regional level to tackle the issues identified previously but not implemented. Members resolved to: • **Note** the background within the report, • **Note** the outcomes of the Neonatal Cot Configuration Project, • **Note** the financial assessment, • **Note** the preferred option of the Project Board, • **Approve** the recommended preferred option and the release of funding in line with the provision within the 2022/25 Integrated Commissioning Plan (ICP) as an interim measure; and • **Did not approve** the recommendation of the Management Group for a phase 2 programme of works to be undertaken, but agreed that the NHS Wales Directors of Planning Group consider the approach to reviewing the neonatal service model, aligning with Health Boards' strategic plans, regional work, and key service interdependencies. The output of the discussion to be brought back to the Joint Committee at a future meeting.
JC23/46	**3.7 IPFR Engagement Update – ToR and All Wales Policy** The report detailing the outcomes from the WHSSC engagement process with key stakeholders to update the WHSSC Individual Patient Funding Request (IPFR) Panel Terms of Reference (ToR) and on the specific and limited review of the All Wales IPFR Policy was received. SL presented the report and members noted the revisions made to the Terms of Reference as a result of the process. SL reported that the majority of responses were accepted and the draft ToR revised accordingly. Two elements were, however, not amended because they were aligned to JC governance. Specifically the requirement for a Corporate Governance Manager being in attendance at IPFR Panel meetings. SL advised that whilst a governance manager would not be in attendance at IPFR panels in HBs, each of the Joint

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	Committee's sub-committees were supported by a governance advisor (Committee Secretary or Head of Corporate Governance). This was to ensure that the Chair and members could seek advice and support on any aspect related to the conduct of their role, and to ensure that the sub-committees decisions on all matters brought before it were taken in an open, balanced, objective and unbiased manner. Therefore, the requirement for the Head of Corporate Governance being in attendance remained in the ToRs. The second element was the authority for signing off urgent IPFR cases which was unchanged from the original version of the ToRs and sits with the Manager of Specialised and Tertiary Services. This is because the WHSSC IPFR / Vice Chair are not WHSSC Officers and therefore do not have any financial delegated limit. In addition, the WHSSC Medical Director and Director of Nursing do not have sufficient delegated financial authority. Members noted that the IPFR engagement working group had accepted all other changes. Members noted that the IPFR Policy review was ongoing and there is further discussion underway with the IPFR Policy Implementation Group and Quality Assurance Group in order to agree a final draft to be submitted to the Joint Committee in May. If supported by JC then HBs will then be asked to take the report to HB Board meetings for final sign off. Members resolved to: • **Note** the report, • **Note** the feedback received from the WHSSC engagement process with key stakeholders to update the WHSSC Individual Patient Funding Request (IPFR) Panel Terms of Reference (ToR) and on the specific and limited review of the All Wales IPFR Policy, • **Approve** the proposed changes to the WHSSC IPFR Panel ToR, • **Note** that the additional feedback on the specific and limited review of the All Wales IPFR Policy is being reviewed and an update will be presented to the Joint Committee on 16 May 2023; and • **Note** that when the limited review of the policy was completed and approved by the Joint Committee, the

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	updated All Wales IPFR Policy (including the WHSSC ToR) will go to each Health Board (HB) for final approval.
JC23/47	**3.8 WHSSC Governance and Accountability Framework – SOs and SFIs** The report providing an update on the WHSSC Governance and Accountability Framework was received. Jacqueline Evans (JE) presented the proposed changes to the Governance and Accountability Framework which incorporates the Standing Orders (SOs) and the Standing Financial Instructions (SFIs) Members noted that the report had been shared with HB Board Secretaries in January 2023 at the request of the Joint Committee for assurance, and that two queries were received concerning the WHSSC process for undertaking a Chair's Action and regarding the financial thresholds. JE had given assurance on both points. JE highlighted that the changes included the update to the designation of the Audit Finance IM Lead to an open and transparent recruitment process open to the seven HBs to advertise into the role. SD informed members that the changes would assist in keeping in alignment with the contract host CTMUHB SFIs. Members resolved to: • **Note** the report, • **Approve** the proposed changes to the Standing Orders (SOs), prior to being issued to the seven HBs for approval and inclusion as schedule 4.1 within their respective HB SOs, • **Approve** the proposed changes of the Memorandum of Agreement (MoA) and Hosting Agreement in place with CTMUHB, prior to being issued to the seven HBs for approval and inclusion as schedule 4.1 within their respective HB SOs; and • **Approve** the proposed changes to the financial scheme of delegation and financial authorisation matrix updating the Standing Financial Instructions (SFIs).

Min Ref	Agenda Item
JC23/48	**4.1 Performance and Activity Report Month 9 2022-2023** The report highlighting the scale of the decrease in activity levels during the peak COVID-19 period, and outlining signs of recovery in specialised services activity was received. The activity decreases were shown in the context of the potential risk regarding patient harms and of the loss of value from nationally agreed financial block contract arrangements. SD highlighted the detail around the three services that had been put into escalation and the improvements that had been made to date. It was noted that Paediatric Surgery had not seen any real improvement in the current performance position and the trajectory going to next year is causing concerns as it appears fairly level. Members noted that the report going forward from next month will see a focus on prospective activity from May rather than what has been delivered pre Covid and post Covid. Members resolved to: • **Note** the report.
JC23/49	**4.2 Financial Performance Report Month 10 2022-2023** The financial performance report setting out the financial position for WHSSC for month 10 2022-2023 was received. The financial position was reported against the 2022-2023 baselines following approval of the 2022-2023 WHSSC Integrated Commissioning Plan (ICP) by the Joint Committee in February 2022. The financial position reported at Month 10 for WHSSC is a year-end outturn forecast under spend of (£14.353m). Members noted that the under spend predominantly relates to releasable reserves of (£18m) arising from 2021-2022 as a result of WHSSC assisting Health Boards to manage resources over financial years on a planned basis, as HBs could not absorb underspends above their own forecasts and to ensure the most effective use of system resources. Members noted that month 11 was not issued at the time papers were submitted but would show a worsened

Min Ref	Agenda Item
	underspend due to the increased activity in C&V UHB which was positive. No queries were raised against the report. Members resolved to: • **Note** the current financial position and forecast year-end position.
JC23/50	**4.3 Neonatal Delivery Assurance Group (DAG) Update** The report providing a summary of South Wales Neonatal Transport Delivery Assurance Group (DAG) Report for July-November 2022 was received. NJ summarised the activity outlined within the highlight report and the incidents that had been reported and the actions taken to implement improvements and incidents that had been resolved by the implementation of the ODN. No queries were raised by members. Members resolved to; • **Note** the information in the report; and • **Receive assurance** that the Neonatal Transport service delivery and outcomes were being scrutinised by the Delivery Assurance Group (DAG).
JC23/51	**4.4 Corporate Governance Matters Report** The report providing an update on corporate governance matters that had arisen since the previous meeting was received. JE highlighted that the annual committee effectiveness survey would be shared with members for completion as well as the annual process for completing Declaration of Interest (DOI) forms. The Chair asked members to try to expedite completion to assist the WHSSC Corporate Governance Team with their records. Members resolved to: • **Note the** report.
JC23/52	**4.5 Reports from the Joint Sub-Committees**

Min Ref	Agenda Item
	The Joint Committee Sub-Committee reports were received as follows: **4.5.1 Audit and Risk Committee (ARC) Assurance Report** The JC noted the assurance report from the CTMUHB Audit and Risk Committee meeting held on 13 February 2023. **4.5.2 Management Group Briefings** The JC noted the core briefing documents from the meeting held on 26 January 2023 and 23 February 2023. **4.5.3 Individual Patient Funding Request (IPFR) Panel** The JC noted the Chair's report from the meeting held on 16 February 2023. **4.5.4 Integrated Governance Committee (IGC)** The JC noted the Chair's report from the meeting held on 16 February 2023. **4.5.5 Quality & Patient Safety Committee (QPSC)** The JC noted the Chair's report from the meeting held on 16 February 2023. CP highlighted the deep dive into Mental Health which each of the HBs had contributed to assisting with the development of the Mental Health Strategy and noted that work is going forward. CS informed members of the increasing concerns being reported in the media around Birmingham hospitals which are a key provider for the Welsh population. In terms of Patient Quality and Safety it was important to monitor the detail. SL confirmed that the matter had been discussed in MG and assured members that it was being monitored. **4.5.6 Welsh Kidney Network (WKN)** The JC noted the Chair's report from the meeting held on 16 February 2023. The Chair highlighted the detail around housing issues raised within the report on behalf of Ian Phillips (IP) who asked that JC members give consideration to raise the detail through regional partnership boards.

Min Ref	Agenda Item
JC23/53	**5.1 Any Other Business** No additional items of business were raised.
JC23/54	**5.2 Date of Next Meeting** The Joint Committee noted that the next scheduled meeting would be on 16 May 2023. There being no other business other than the above the meeting was closed.
JC23/55	**5.3 In Committee Resolution** The Joint Committee recommended to make the following resolution: "That representatives of the press and other members of the public be excluded from the remainder of this meeting having regard to the confidential nature of the business to be transacted, publicity on which would be prejudicial to the public interest" (Section 1 (2) Public Bodies (Admission to Meetings) Act 1960)".

Chair's Signature: .....

Date:.....

GIG CYMRU NHS WALES
Pwyllgor Gwasanaethau Iechyd Arbenigol Cymru (PGIAC)
Welsh Health Specialised Services Committee (WHSSC)

JOINT COMMITTEE MEETING
Action Log 16 May 2023

Action Ref	Minute Ref and Action	Owner	Due Date	Progress	Status
8 November 2022					
JC22/026	**JC22/134 Delivering Thrombectomy Capacity in South Wales** **ACTION:** The Delivering Thrombectomy Capacity in South Wales report and accompanying documents to be updated to provide greater emphasis on the networked approach, interdependencies around the network approach and pick up additional elements including the stroke review. The updated report should be presented to the JC in March 2023 for further discussion.	NJ	March 2023	**27.04.2023 –** The item was considered by the Joint Committee on the 14 March 2023. Action completed.	**CLOSED**
JC22/029	**JC22/138 Individual Patient Funding Request (IPFR) Governance Engagement Update**	SL	March 2023	**27.04.2023 –** The item was considered by the Joint Committee on the 14 March 2023. Action completed.	**CLOSED**

Action Ref	Minute Ref and Action	Owner	Due Date	Progress	Status
	ACTION: An update on the Individual Patient Funding Request (IPFR) Engagement process to be provided to the JC in early 2023.				
JC23/001	**JC23/31 Integrated Commissioning Plan (ICP) 2023-2024** **ACTION:** NHSE funding growth approach to be considered at a future JC session with a discussion on the variation and impact of investment between Scotland, England and Wales.	SD/NJ	July 2023	**Not yet Due.**	**OPEN**
	ACTION: A review of the potential impacts on providers in Wales on strategic reinvestment, disinvestment and any subsequent reconfiguration to be discussed at a future JC meeting.	SD/NJ	July 2023	**Not yet Due.**	**OPEN**
	ACTION: An outline governance system and process for the Joint Committee to monitor achievement of the 1% WHSSC and HB shared pathway savings target be brought back to the Joint Committee for approval on 14 March 2023.	SD/NJ	March 2023	**27.04.2023 –** The item was considered by the Joint Committee on the 14 March 2023. Action completed.	**CLOSED**

Action Ref	Minute Ref and Action	Owner	Due Date	Progress	Status
14 March 2023					
JC23/003	**JC23/39 Governance System and Process – WHSSC & HB Shared Pathway Saving Target** **ACTION –** NJ to present milestones on the Governance System and Process – WHSSC & HB Shared Pathway Saving Target to the Joint Committee meeting 16 May 2023.	NJ	May 2023	**19.04.2023** On the agenda for 16 May 2023 JC meeting.	**OPEN**
JC23/004	**JC23/43 Eating Disorder In-Patient Provision for Adults** CS advised it was important to ensure that patients did not need to travel long distances for treatment, and queried the weighting criteria and asked if there were measures to monitor outcomes and the difference that had been achieved by the providers with experience of improvement in the facilities. DR responded and advised that it may not be possible to run a unit within Wales due to the specialist skills required and therefore the patient need was balanced against access and proximity together with the skills and expertise of the relevant independent sector provider.	DR	July 2023	**27.04.2023 –** due to the NHS Wales Shared Services Partnership (NWSSP) encountering delays associated with the specification of a Welsh location within the procurement tender, an update will now be given in the Summer.	**OPEN**

Action Ref	Minute Ref and Action	Owner	Due Date	Progress	Status
	ACTION: DR will circulate the proposed weighting criteria to members following the meeting.				
JC23/005	**JC23/45 Neonatal Cot Configuration Project** Members noted that the phase 1 element of the work was supported and NJ suggested that phase 1 would provide a good foundation to take forward phase 2. NJ agreed there would be value in taking forward a piece of work with the NHS Wales Directors of Planning Peer Group and would take it there for an initial discussion. Further consideration will then be needed around the scope of the work and the decision making process to implement changes. **ACTION:** NJ to meet with the NHS Wales Directors of Planning (DoP) peer group for initial discussions on phase 2 of the work for the Neonatal Cot Configuration Project.	NJ	July 2023	**19.04.2023** Meeting scheduled with the NHS Wales DoPs peer group week commencing 5 May 2023. **Not yet due.**	**OPEN**
	Members noted that a risk assessment had been undertaken through the Finance Management Sub	SD	April 2023	**03.05.2023 –** a financial options appraisal was considered by the Management Group Finance Sub	**CLOSED**

Action Ref	Minute Ref and Action	Owner	Due Date	Progress	Status
	Group and financial flows and impact on organisations had been mapped for Phase 1. **ACTION:** The risk assessment and Financial flow information to be shared with Joint Committee members.			Group in February and was subsequently circulated to providers to agree the 2022/23 in year funding release circulated to JC members. Action completed.	

Report Title	**Specialised Services Commissioning Strategy**	**Agenda Item**	2.1
Meeting Title	**Joint Committee**	**Meeting Date**	16/05/2023
FOI Status	Open		
Author (Job title)	Project Manager		
Executive Lead (Job title)	Managing Director, WHSSC		

Purpose of the Report	The purpose of this report is to present the final draft of the Specialised Services Commissioning Strategy for approval.				
Specific Action Required	RATIFY ☐	APPROVE ☒	SUPPORT ☒	ASSURE ☐	INFORM ☐

Recommendation(s):

Joint Committee is asked to:

- **Approve** the final draft of the Specialised Services Commissioning Strategy; and
- **Support** the decision to undertake further detailed work on the development of a set of meaningful success measures for the strategic objectives, with a timescale of September 2023 for completion.

SPECIALISED SERVICES COMMISSIONING STRATEGY UPDATE

1.0 SITUATION

The purpose of this report is to present the final draft of the Specialised Services Commissioning Strategy for approval.

Further work is required on the development of a set of meaningful success measures for the strategic objectives, with a timescale of September 2023 for completion.

2.0 BACKGROUND

In line with WHSSC Standing Orders (SO's), the role of the Joint Committee is to determine a long-term strategic plan for the development of specialised and tertiary services in Wales, in conjunction with the Welsh Ministers. In addition, the May 2021 Audit Wales Report into the Committee Governance Arrangements at WHSSC included a number of recommendations related to developing a new specialised services strategy. The report advised that, *"Post COVID-19, developing a strategy would now provide opportunity to shape the direction to focus on recovery, value, and to exploit new technologies and innovative ways of working".*

As agreed at Joint Committee meeting on 6 September 2022, a 12 week engagement process was undertaken, which concluded in December 2022, to inform and support the development of an overarching commissioning 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.

3.0 ASSESSMENT

The Strategy will set the organisation's guiding purpose and direction and form the basis for strategic planning through the Integrated Commissioning Plan (ICP) cycle. A workshop was therefore undertaken with WHSSC staff to provide an overview of the stakeholder feedback and to give staff the opportunity to comment on the emerging strategic aims and objectives. WHSSC staff from across the organisation have also been involved in the development work around the success measures.

Regular updates on progress have been presented to the Management Group (MG) on the outcomes of the engagement process and through the development stage of the strategy. In particular, members were assured that there were no 'surprises' within the feedback received, which reaffirmed what is important to stakeholders when commissioning specialised services and the key role that WHSSC has to play as the lead commissioner. The session also gave members the opportunity to comment on the emerging strategic aims and objectives.

A workshop was undertaken with Joint Committee members on 17 April 2023 with a particular focus on the strategic aims and objectives, and discussion on a few specific areas that came up through the engagement process concerning performance management, pathway management and WHSSC's role in supporting a national approach to the commissioning of services that may not be considered specialised.

Feedback from the workshop has been taken on board, specifically:

- There should be robust performance management in place, in line with the principles of honesty and openness, and that escalation processes are geared to support this;
- That WHSSC should be fully involved in pathway development and that it would be useful to agree the priority areas;
- That quality should be made more visible to the MG alongside the reporting of service delivery, performance and finance; and
- That clarity is required around what the term recommissioning means in terms of value, the achievement of service delivery and anticipated outcomes, and decommissioning where appropriate.

Further work has been ongoing to edit and refine the strategy document which has also been shared with Welsh Government (WG) for comment, with a deadline for comments to be received by 4 May 2023.

The Joint Committee are requested to approve the final draft presented at ***Appendix 1*** prior to publication at the end of May 2023.

Work is underway on building a set of meaningful success measures against which we can monitor and assess achievement of the strategic aims and objectives. It is recognised that a number of these may be more difficult to quantify and measure, particularly for those that may be reliant on Health Board (HB) data and reporting. Further thought and consideration will be needed with the MG before these can be finalised. Consequently, it is suggested that we aim to finalise the measures by September (Qtr. 2) in readiness to feed into the next ICP process. The measures within the published strategy will therefore be outlined but the detail will remain under development at this stage.

4.0 RECOMMENDATIONS

The Joint Committee is asked to:

- **Approve** the final draft of the Specialised Services Commissioning Strategy; and
- **Support** the decision to undertake further detailed work on the development of a set of meaningful success measures for the strategic objectives, with a timescale of September 2023 for completion.

Governance and Assurance	
Link to Strategic Objectives	
Strategic Objective(s)	Development of the Plan Governance and Assurance
Link to Integrated Commissioning Plan	Developing a Specialised Services Commissioning Strategy for the Residents of Wales
Health and Care Standards	Safe Care Effective Care Governance, Leadership and Accountability
Principles of Prudent Healthcare	Only do what is needed Reduce inappropriate variation Care for Those with the greatest health need first
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 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.
Organisational Implications	
Quality, Safety & Patient Experience	The aim of the Specialised Services Commissioning Strategy is to improve patient outcomes through expert national commissioning, ensuring the delivery of high quality, sustainable healthcare services for the people of Wales which are responsive to change, accessible, and maximise value and outcomes within available resources.
Finance/Resource Implications	No specific resource implications outlined within the report. However any strategic decision identified as a result of the development of the strategy such as a transfer of service, would require financial assessment.
Population Health	To ensure equitable access for all patients in Wales.
Legal Implications (including equality & diversity, socio economic duty etc.)	As identified within the EQIA
Long Term Implications (incl. WBFG Act 2015)	_
Report History (Meeting/Date/ Summary of Outcome	Corporate Directors Group Board (CDGB) – 14 July 2022 – Approved Management Group – 28 July 2022 – Supported Management Group – 25 August 2022 – Supported Joint Committee – 6 September 2022 – Supported Management Group – 24 November 2022 - Noted

	Management Group – 15 December 2022 – Noted Management Group – 23 February 2023 – Noted Corporate Directors Group Board (CDGB) – 06 March 2023 – Supported Management Group – 23 March 2023 – Supported Joint Committee Workshop – 17 April – Supported Corporate Directors Group Board (CDGB) – 02 May 2023 – Supported
Appendices	Appendix 1 – WHSSC Specialised Services Commissioning Strategy v22

Specialised Services Commissioning Strategy

2023 – 2033

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

'Improving Patient Outcomes through Expert National Commissioning'

"We seek to ensure the delivery of high quality, sustainable healthcare services for the people of Wales which are responsive to change, accessible, and maximise value and outcomes within available resources"

Contents

1. Foreword

We are pleased to present the Welsh Health Specialised Services Committee's (WHSSC) Specialised Services Commissioning Strategy, which sets out the overall vision and priorities for the commissioning of Specialised Services for the Welsh population between 2023 and 2033, and sets the context for all other Specialised Services strategic developments.

Every person in Wales who uses health services or supports others to do so, whether in hospital, primary care, their community or in their own home has the right to receive excellent care as well as advice and support to maintain their health. All health services in Wales need to demonstrate that they are doing the right thing, in the right way, in the right place, at the right time and with the right staff.

The aim of this Specialised Services Commissioning Strategy is to ensure that the residents of Wales can now, and in the future, receive equitable access to high quality specialised services, which are clinically effective, and that offer the best outcomes and experience for patients, as well as providing the greatest value for our population.

Development of the strategy post COVID-19 has provided us with the opportunity to shape the direction to focus on recovery, value, and to exploit new technologies and innovative ways of working.

Key to this is the recognition of the diverse relationships that exist between North, Mid and South Wales with Welsh Providers and NHS England where both patient pathways and direct access to specialised services differ. The objective of this strategy is therefore to define the overall approach for Wales to the future development of specialised services from a local, regional and national perspective, our priorities in relation to the wider NHS and our priorities within specialised services.

Dr Sian Lewis
Managing Director

Kate Eden
Chair

Work is underway building a set of meaningful success measures against which we can monitor and assess achievement of our strategic aims and objectives, with a timescale of September 2023 for completion. The measures within this strategy are therefore outlined, however the detail will remain under development.

Because of the pace of change in specialised services, we will review this strategy in 5 years to consider whether it remains fit for purpose for the following 5 year period.

We would like to thank you for taking the time to read our plans and ambitions, and for your input in developing

2. What You Told Us

Welcome to our new ten-year strategy for specialised services for the residents of Wales and our responsible population. Our strategy sets out what we will do between now and 2032.

The strategy has been developed over a number of months, based on the feedback we received from our engagement exercise with key stakeholders within the NHS in Wales and England, as well as wider organisations across health, social care and the third sector representing the patients voice.

In bringing the strategy together, we have reflected on the ideas, suggestions and priorities put forward to understand what they think and would like us to do differently.

These are some of the things you said to us:

- Collaborate with NHS England to establish cross border networks to ensure resilience in the system
- Incentivise and celebrate good practice and over performance in services
- WHSSC could have a 'Once for Wales' role for fragile services, or where specialist skills, workforce or equipment are required
- Services should be commissioned on evidence based outcomes and value based commissioning
- Increased emphasis on population health needs assessment to underpin all future commissioning decisions
- Ensuring equity for all residents of Wales no matter where they access services
- Offer shadowing, secondments and rotation of staff between WHSSC and Health Boards to share knowledge, expertise and learning
- Define commissioner responsibilities across the whole of the patient pathway
- Seek alternative provision where it is in the patients best interest to do so
- Stronger engagement and increased focus on patient experience and the public voice
- Distance and access to services should be a key driver for digital innovation
- Poor performance should be actively addressed, holding services to account for delivery
- Where appropriate, commission services in Wales to necessitate investment and drive quality, efficiency and specialisation within our workforce
- Greater visibility and transparency, with public accessibility, on performance, quality and patient safety information
- Ensure alignment with Health Board priorities and strategies
- Drive research and innovation and support to publish papers

3. Background

The Welsh Health Specialised Services Committee (WHSSC) was established in 2010 as a Joint Committee of each local health board in Wales, established under the WHSSC (Wales) Directions 2009 (2009/35). The remit of the Joint Committee is to enable the seven health boards in Wales to make collective decisions on the review, planning, procurement, and performance monitoring of agreed specialised and tertiary services.

WHSSC has an overall annual budget of over £752 million with the financial contributions determined by population need. Typically, WHSSC spends two thirds of its budget within NHS Wales and one third within NHS England.

On a day-to-day basis, the Joint Committee delegates operational responsibility for commissioning to WHSSC Officers, through a management team supported by six multidisciplinary commissioning teams and one clinical network. A list of the services that WHSSC is currently responsible for commissioning can be found in Appendix 1. Not all specialised services, as defined in the NHS England Prescribed Services Manual, have been delegated to WHSSC and some remain the commissioning responsibility of health boards.

Specialised services generally have a high unit cost as a result of the nature of the treatments involved and are provided to a smaller number of patients compared to routine services and treatments. They are not available in every local hospital because they have to be delivered by specialist teams who have the necessary skill, equipment and experience, and cover conditions such as rare cancers, genetic disorders, severe mental health and complex medical and surgical disorders. The particular features of specialised services, such as the relatively small number of centres and the unpredictable nature of activity, require robust planning and assurance arrangements to be in place to make the best use of scarce resources and to reduce risk.

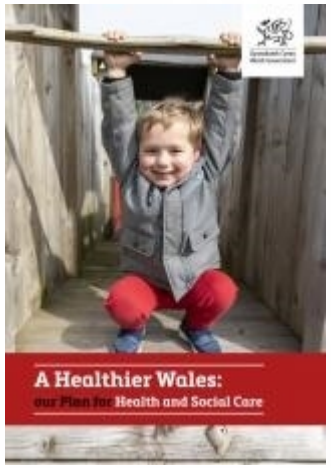
This strategy encompasses not only current WHSSC and health board commissioned specialised and highly specialised services, but also recognises their evolution, and therefore the approach to commissioning new services. As the strategy looks ahead 10 years, many new technologies and practices are unknown fully and are still emerging. Therefore, WHSSC will need to provide a commissioning system that can respond to Health Board and Welsh Government priorities with urgency and agility as new opportunities arise.

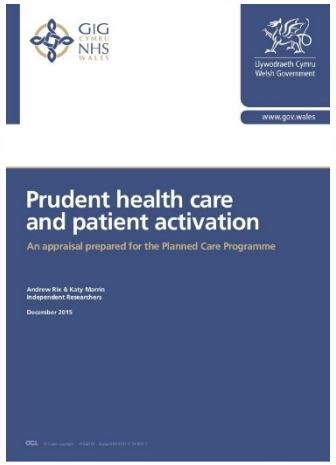
The role of WHSSC and health boards in non-specialised commissioned services where pathway development directly impacts on access to specialised and highly specialised services have been considered as part of this strategy. As part of the service reviews, WHSSC, alongside health boards, will use a recommissioning approach to pathway development and service change and where evidenced will redeploy resources further up the pathway.

In addition, this strategy reflects the role of partnerships with a view to strengthening and developing new ones. This includes NHS partners inside and outside Wales as well as non-NHS partners such as the Third Sector, Social Care, Universities and the Llais Wales.

4. Context

The last specialised services commissioning strategy was published in 2012. During the intervening period there has been significant challenge related to the rapid pace, and often unpredictable development of innovative treatments, an increasingly austere financial climate and more recently the unprecedented and disruptive impact of the COVID-19 pandemic on NHS care. A key focus of this strategy therefore is on WHSSC's ability and agility to respond to evolving challenges and risks as they present themselves.





The policy context within NHS Wales has also changed during this time and the strategy needs to align to a number of major policy developments including Welsh Government's "a Healthier Wales: Long Term Plan for Health and Social Care" (2021), Prudent Health Care (2018), Welsh Government's NHS Quality & Safety Framework , the provisions of the Health and Social Care (Quality and Engagement) (Wales) Act 2020, in relation to the new duty of quality and duty of candour, and of course the Well-being of Future Generations Act 2015.

Wales has its own distinctive approach to health and care provision. Integration and co-operation between health organisations is a key principle of healthcare policy, along with a commitment to avoid duplication and do things 'Once for Wales'. To realise the benefits of an integrated health and care system in Wales, it is vital to secure the best possible services through effective commissioning. Through a recommissioning approach, services can also be decommissioned where they are no longer needed, could be better provided elsewhere, or are not providing the expected outcomes or value. NHS Wales established WHSSC in order to support collaborative commissioning and as health boards and trusts develop integrated care and services with local authorities, collaborative approaches based on evidence must play through in these joint commissioning arrangements to ensure shared values, common goals and joint aspirations. It is important to recognise that a number of specialised services remain the commissioning responsibility of individual health boards and may be better commissioned by WHSSC, if value could be added through a once for Wales approach.

4. Context

In May 2021, Audit Wales published its report on the "Welsh Health Specialised Services Committee Governance Arrangements". The report found that since the previous reviews in 2015, governance, management and planning arrangements have improved, but the impact of COVID-19 now required a clear strategy which would now provide opportunity to shape the direction to focus on recovery, value, and to exploit new technologies and innovative ways of working.

In addition to the Welsh context, in July 2022 the Health and Care Act 2022 for NHS England (NHSE) legally established 42 Integrated Care Systems (ICSs). Each ICS will have an Integrated Care Board (ICB), a statutory NHS organisation responsible for developing a plan for meeting the health needs of the population, managing the NHS budget and arranging for the provision of health services in the ICS area.

Through this new legislation, ICBs have also been given the opportunity to take on delegated responsibility from April 2023, where appropriate, for specialised services but within a framework of continued national accountability, national standards, national service specifications and national clinical policies. NHSE has recognised that not all specialised services will be suitable, or ready, for delegation to ICBs. Where this is the case there will be a further year of transition with additional support so they are ready to take on full delegated responsibility from April 2024.

WHSSC will continue its well established relationship at a national level with NHSE Specialised Commissioning and will continue to develop relationships at a regional level and with the new ICSs who will have an influence on the future direction for some of our providers in England of national and regional/supra-regional services. This will be of particular importance for patients from North and Mid Wales.

Alongside all these policy changes, we have an ageing population and increasing number of treatment options for patients with more advanced disease, all creating a growing demand for specialised services. It is against this backdrop that it has becoming increasingly important that we renew the strategy and ensure it can meet the needs of the population of Wales for the next 10 years.

A PESTLE analysis has been undertaken across a range of factors to take advantage of opportunities and mitigate threats to WHSSC's functions in the development and achievement of our strategic aims (see Appendix 2). This has been used to inform our strategy development.

5. National Commissioning Functions Review

In 2018 when a Healthier Wales was published, the Welsh Government signalled an intention to review a range of hosted national functions alongside the establishment of the NHS Executive. In January 2023, a review of National Commissioning Functions was announced by Welsh Government which will conclude in May 2023. The development of our specialised services commissioning strategy continued alongside this, with the aim of agreeing the strategy in the context of the recommendations of the review when concluded.

National commissioning is vital in improving the outcomes for the population of Wales and in reducing any inequalities in access. The review is an opportunity to reflect upon the experiences of WHSSC, the Emergency Ambulance Services (EASC), and the National Collaborative Commissioning Unit (NCCU), and to further build upon and strengthen national commissioning arrangements.

The Review will identify options and make recommendations about the future configuration of national commissioning and national commissioning organisations, EASC, WHSSC and the NCCU. The final recommendation will be made by the Chief Executive of the NHS in Wales for the Minister for Health and Social Services to make a final decision. It is expected both Joint Committees of WHSSC and EASC to be integral to supporting this work and during the review.

The review recommendations will be founded on the following principles:

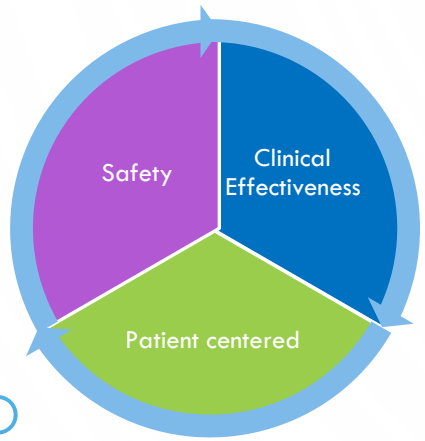
- Improving outcomes and reducing inequalities
- Adding further value to the NHS system in Wales
- Strengthening and streamlining of commissioning functions, and associated decision making
- Building on evidence of good practice
- Supporting the development of commissioning expertise within the NHS in Wales
- Maximisation of national commissioning capacity and capabilities
- Minimal disruption to the system

Whilst this strategy has not pre-empted the outcome of the review, the above principles have been reflected as a theme throughout the strategic aims and objectives.

6. Quality and Patient Safety

WHSSC recognises the key importance of patients being able to access safe, effective specialised services that provide excellent user experience. In line with the new statutory Duty of Quality in Wales, the quality of care and experience that patients and their families receive is therefore central to the commissioning of specialised services. A focus on improving the quality of care and population outcomes is everyone's business and all of our staff strive to ensure that quality and patient centred services are at the heart of commissioning.

The WHSSC Quality Framework was first developed in July 2014 with the purpose of setting the direction for the quality assurance of services and providing a structure for both the commissioning and provider element of specialised and tertiary services for the population of Wales. In 2021, the framework was revised and renamed the Commissioning Assurance Framework (CAF) to encompass all of the components necessary to provide assurance to Health Boards and the public that WHSSC commissions high quality clinical care and there are robust processes in place to monitor services and where there is concern regarding the quality of services and remedial action is required escalation processes are initiated and acted upon in a timely manner.



The aim of the Commissioning Assurance Framework (CAF) is to move beyond the basic infrastructure to the next stage of driving quality assurance and more importantly improvement in our specialised commissioned services. The fundamental principles underpinning the Commissioning Assurance Framework are to develop open and transparent relationships with our providers, to engage and involve the clinical teams and work in partnership with stakeholders when planning and commissioning services. This requires a facilitative and proactive approach where intervention as early as possible is key in order to provide support to services where issues of concern are identified.

A key element of commissioning services 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.

Patient Experience and Engagement

Good experience of care, treatment and support is an essential part of an excellent health and social care service. A person's experience starts from their very first contact with a service, through to their last. We want to broaden our approach to engage with patients, their families and carers to support the shaping of our future service commissioning, to make it easier for the patients voice to be heard and to learn from their lived experiences. WHSCC is keen to increase its work with patient advocacy groups, and health providers to support this approach.

7. Decarbonisation and the Foundational Economy

Decarbonisation

Welsh Government declared a Climate Emergency in 2019 and expects the public sector to be net zero by 2030. The NHS Wales Decarbonisation Strategic Delivery Plan was published on 24 March 2021.

WHSSC is committed to taking assertive action to reducing the carbon footprint through mindful commissioning of services that take account of the decarbonisation agenda, where possible, providing services closer to home by enabling enhanced digital and virtual access for patients. 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 from the commencement of the 2022-2023 year all policies will contain a decarbonisation statement and a focus on innovative ways of working.

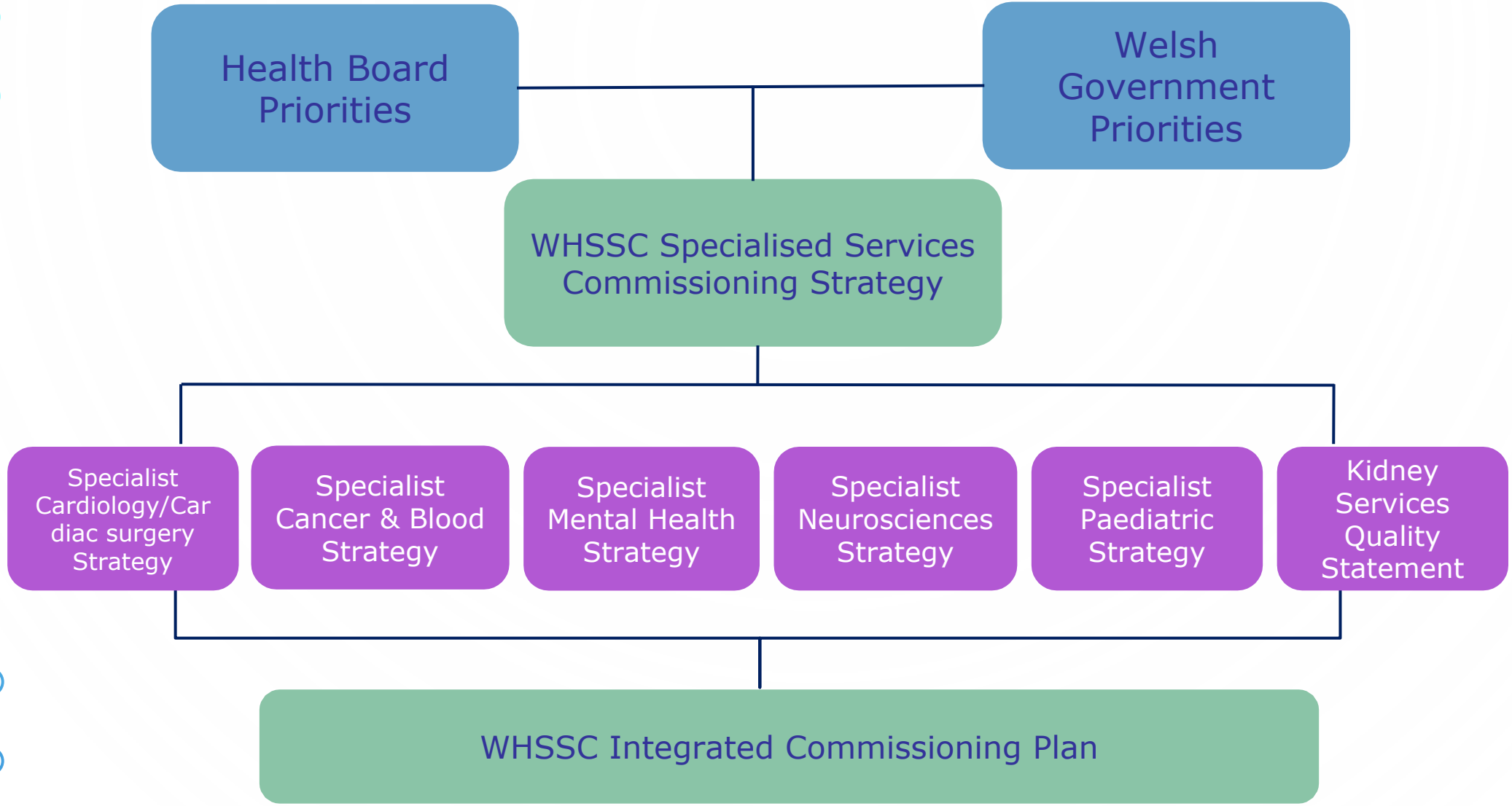
Foundational Economy

The Foundational Economy is an approach taken by the Welsh Government to ensure that funding improves the way the local economy works in Wales by developing the growth to vital services and goods.

Through working in partnership and Welsh Government, over the last decade WHSSC has supported significant investment into moving care closer to home and creating services based in Wales. It is estimated that the £45m revenue investment has created over 750 high quality and stable employment jobs within NHS Wales, whilst also moving services out of the main specialist centres into more local settings in West and North Wales. WHSSC's ambition is to continue developing services closer to home by creating new services within Wales and repatriating activity from the private sector providers and NHS England where it is appropriate to do so.

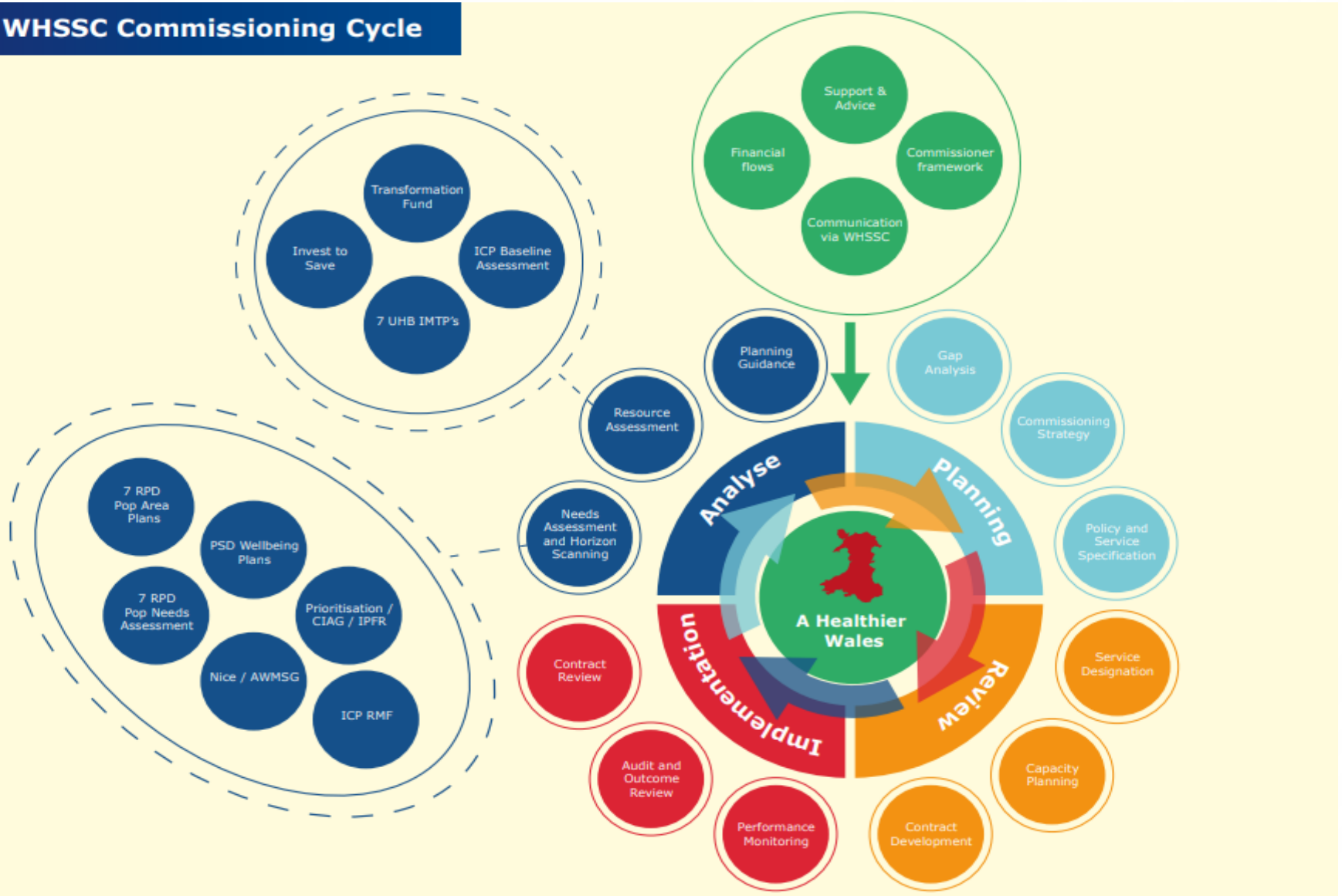
To deliver this work, we will review our contracts with a view to delivering within Wales where it is safe and effective to do so. Through appropriate engagement and consultation we will develop implementation plans to deliver services as accessible from home as possible, through digital and alternative delivery models. And, working in partnership with providers external to Wales, we will look to repatriate parts of pathways that could be delivered locally where it is not appropriate or possible to deliver wholly in Wales.

8. Strategic Alignment



9. WHSSC Commissioning Cycle

Diagram 1: WHSSC Commissioning Cycle



10. Our Strategy on a Page

Our Vision What is our goal?	**'Improving Patient Outcomes through Expert National Commissioning'**				
Our Mission What will we do to achieve our goal?	We seek to ensure the delivery of high quality, sustainable healthcare services for the people of Wales which are responsive to change, accessible, and maximise value and outcomes within available resources				
Our Values What matters to us?	**RESPECT**  We will listen to everyone's view We will treat people fairly We will recognise everyone's contribution		**PARTNERSHIP**  We will work as a team We will communicate effectively We will build strong and inclusive relationships We will be positive role models		**IMPROVEMENT & INNOVATION**  We will continuously learn We will strive for excellence We will accept challenge and opportunity
Our Strategic Aims What do we want to achieve?	1. To ensure the provision of safe, high-quality services for the people of Wales	2. To plan for the long term to ensure sustainable, accessible service provision for the residents of Wales, which is responsive to change	3. To provide an expert approach to national healthcare commissioning	4. To be an effective partner, supporting service and system transformation	5. To maximise value and outcomes within available resources

11. Our Strategic Aims and Objectives

Our Strategic Aims What do we want to achieve?	1. To ensure the provision of safe, high-quality services for the people of Wales	2. To plan for the long term to ensure sustainable, accessible service provision for the residents of Wales, which is responsive to change	3. To provide an expert approach to national healthcare commissioning	4. To be an effective partner, supporting service and system transformation	5. To maximise value and outcomes within available resources
Our Strategic Objectives How will we achieve this?	1.1 To commission safe, high-quality services by ensuring the STEEEP principles are at the heart of all our work 1.2 To be an evidence-based commissioner, securing clinically effective services 1.3 To promote equitable provision of services and minimise unwarranted variation 1.4 To ensure services are as efficient and timely as possible for all patients 1.5 To continuously improve patient experience and engagement through our commissioning activities.	2.1 To ensure services are commissioned on a robust assessment of population health need 2.2 To become a strategic commissioner, planning for all service areas for the long-term 2.3 To commission and maintain sustainable services from designated providers 2.4 To encourage innovation and responsiveness in service design and provision through commissioning mechanisms 2.5 To ensure services are as accessible as possible through use of digital opportunities 2.6 To encourage robust workforce redesign and provision through commissioning	3.1 To be an expert commissioner for services where a national or regional approach is required 3.2 To act as a system expert to enhance and develop commissioning capacity and capability for NHS Wales	4.1 To work in partnership with Health Boards to maximise the benefits of national commissioning in NHS Wales 4.2 To foster partnerships with NHS England commissioners and providers to improve services for Welsh patients 4.3 To ensure a whole system approach to pathway management to reduce unintended consequences	5.1 To maximise the use of core resources by recommissioning services where necessary 5.2 To focus on improving strategic, service and patient outcomes 5.3 To achieve the greatest value for money for the Welsh population

12. Strategic Objectives and Measures of Success

Strategic Aim 1. To ensure the provision of safe, high-quality services for the people of Wales		
Why is this Important? The quality of care and experience that patients and their families receive is central to our commissioning. Quality is everyone's business and as a national organisation working on behalf of the 7 Health Boards we have a duty to continuously improve the quality of services delegated to us.		
Strategic objectives	**How will we do this?**	**How will we measure success?**
1.1 To commission safe, high-quality services by ensuring the STEEEP principles are at the heart of all our work	We will continuously use our published Commissioner Assurance Framework and Escalation Frameworks to ensure the quality and safety of commissioned services	• Measures related to the Escalation Framework • Measures related to service reviews
1.2 To be an evidence-based commissioner, securing clinically effective services	We will continuously use clinical evidence, GIRFT reports, benchmarking, outcomes and other comparative information to develop our integrated Commissioning Plan, service specifications and commissioning policies We will continue to use robust prioritisation methodology, aligned to system priorities, to make effective, evidence-based commissioning decisions and plans	• Measures related to the development of service specifications and commissioning policies • Measures related to the horizon scanning and the prioritisation process

12. Strategic Objectives and Measures of Success

Strategic Aim 1. To ensure the provision of safe, high-quality services for the people of Wales		
Why is this Important? The quality of care and experience that patients and their families receive is central to our commissioning. Quality is everyone's business and as a national organisation working on behalf of the 7 Health Boards we have a duty to continuously improve the quality of services delegated to us.		
Strategic objectives	**How will we do this?**	**How will we measure success?**
1.3 To promote equitable provision of services and minimise unwarranted variation	We will continue to develop our systems to measure and report on unwarranted variation in service provision, using Business Intelligence and comparative information We will work with Health Boards and Trusts to promote mutual understanding and plans to reduce variation for their commissioned populations We will continue to apply the WHSSC Referral Management Policy to minimise inequities and unwarranted variation of referrals outside of Wales	• Measures related to Service Improvement and Innovation Days • Measures related to referral gatekeeping
1.4 To ensure services are as efficient and timely as possible for all patients	We will plan to improve the efficiency and timeliness of service provision in line with the Ministerial Measures and system priorities We will monitor and manage performance and delivery of our contracted services in line with our Performance Management Framework	• Measures related to efficiency targets as part of the ICP process and commissioning intentions • Measures related to contract performance
1.5 To continuously improve patient experience and engagement through our commissioning activities.	We will use our published Patient Engagement and Experience Framework to ensure patients have a voice in commissioning the services delegated to us We will develop and implement a systematic approach to collecting and using PROMS and PREMS in our commissioning activities	• Measures related to the collection of PROMS and PREMS • Measures related to patient engagement

12. Strategic Objectives and Measures of Success

Strategic Aim 2. To plan for the long term to ensure sustainable, accessible service provision for the residents of Wales, which is responsive to change

Why is this Important? We aim to become a strategic commissioner, planning to put services on a longer term sustainable footing and improve access for patients. We know that the pace of change is accelerating and we need to be agile to respond to developments in the wider environment that will impact the services we commission, as well as playing our part in the decarbonisation of NHS Wales.

Strategic objectives	How will we do this?	How will we measure success?
2.1 To ensure services are commissioned on a robust assessment of population health need	We will partner with NHS and academic bodies to implement a systematic approach to health needs assessment When we develop our service specific commissioning strategies we will use a systematic approach based on population health needs assessment as well as outcomes and evidence of effectiveness	• Measures related to developing a partnering approach for health needs assessment • Measures related to service commissioning strategies based on population health needs assessment
2.2 To become a strategic commissioner, planning for all service areas for the long-term	Through engagement with Health Boards and NHSE specialised providers we will develop and implement a clinically-led 5-year service-specific commissioning strategy for each of our portfolios / groups of services Our Commissioning Intentions and commissioning plans will be based on the service strategies, enabling medium-term financial and service planning We will play our part in the NHS in Wales becoming carbon net-zero by 2030	• Measures related to service commissioning strategies for each commissioning portfolio • Measures related to Integrated Commissioning Plan developments • Measures related to carbon reduction

12. Strategic Objectives and Measures of Success

Strategic Aim 2. To plan for the long term to ensure sustainable, accessible service provision for the residents of Wales, which is responsive to change		
Why is this Important? We aim to become a strategic commissioner, planning to put services on a longer term sustainable footing and improve access for patients. We know that the pace of change is accelerating and we need to be agile to respond to developments in the wider environment that will impact the services we commission, as well as playing our part in the decarbonisation of NHS Wales.		
Strategic objectives	**How will we do this?**	**How will we measure success?**
2.3 To commission and maintain sustainable services from designated providers	We will review and recommission services on a systematic basis to promote sustainable service models We will use our published Designated Provider process to secure new providers for services where required	• Measures related to service fragility • Measures related to the review of services and service specifications • Measures related to Service Improvement and Innovation Days
2.4 To encourage innovation and responsiveness in service design and provision through commissioning mechanisms	We will collaborate with providers and partners including the NHS Innovation services, NHS England Specialised Commissioning and others to continuously horizon scan and evaluate new research, treatment and guidance to inform our commissioning plans and policies	• Measures related to innovation

12. Strategic Objectives and Measures of Success

Strategic Aim 2. To plan for the long term to ensure sustainable, accessible service provision for the residents of Wales, which is responsive to change		
Why is this Important? We aim to become a strategic commissioner, planning to put services on a longer term sustainable footing and improve access for patients. We know that the pace of change is accelerating and we need to be agile to respond to developments in the wider environment that will impact the services we commission, as well as playing our part in the decarbonisation of NHS Wales.		
Strategic objectives	**How will we do this?**	**How will we measure success?**
2.5 To ensure that where appropriate, services are as accessible as possible through use of digital opportunities	We will use a Digital First approach to commissioning; working with Directors of Digital to develop a brief digital commissioning tool to encourage and incentivise accessibility, efficiency and innovation	• Measures related to digitally led approaches
2.6 To encourage robust workforce redesign and provision through commissioning	We will encourage and incentivise workforce redesign and innovation through our planning and commissioning processes to ensure sustainable and high quality services We will work with HEIW on targeted initiatives to address workforce shortages and fragility in the services delegated to us	• Measures related to service fragility • Measures related to the alignment of the ICP with National Education and Training Plan (HEIW)

12. Strategic Objectives and Measures of Success

Strategic Aim 3. To provide an expert approach to national healthcare commissioning		
Why is this Important? There is renewed interest in healthcare commissioning as a tool for change and improving value in NHS Wales, and we believe we can share our expertise, skills and experience to help the system to develop in this area.		
Strategic objectives	**How will we do this?**	**How will we measure success?**
3.1 To be an expert commissioner for services where a national or regional approach is required	We will use our expert commissioning skills and expertise to add value to the NHS Wales system through commissioning services delegated to us by Health Boards or Welsh Government We will develop a Commissioning Framework, based on best practice adapted for the Welsh system to lay out our standard commissioning cycle and methodology	• Measures related to the Commissioning Framework
3.2 To act as a system expert to enhance and develop commissioning capacity and capability for NHS Wales	We will provide leadership for the development of healthcare commissioning skills and expertise in NHS Wales We will develop a suite of commissioning tools and learning and development opportunities in conjunction with Health Boards, Welsh Government and the Directors of Planning Peer Group / Assistant Directors of Commissioning.	• Measures related to commissioning learning and development

12. Strategic Objectives and Measures of Success

Strategic Aim 4. To be an effective partner, supporting service and system transformation		
Why is this Important? We work on behalf of the 7 Health Boards in Wales and we need to work effectively and transparently with the NHS in both Wales and England to provide excellent services for the whole of the Welsh population.		
Strategic Objectives	**How will we do this?**	**How will we measure success?**
4.1 To work in partnership with Health Boards to maximise the benefits of national commissioning in NHS Wales	We will aim to be a good partner, working collaboratively and with integrity at all levels of service delivery to deliver system benefits We will ensure robust, open and transparent decision-making and governance is in place for commissioning on behalf of Health Boards across NHS Wales	• Measures related to reputation and status • Measures related to commissioner partnerships • Measures related to the Performance Management Framework
4.2 To foster partnerships with NHS England commissioners and providers to improve services for Welsh patients	We will work collaboratively with NHSE Specialised Services Commissioners and ICBs to promote innovation and sustainability of service delivery We will systematically review and recommission services with Health Boards to make appropriate decisions about the location of services for border populations We will maintain our all-Wales focus including our North Wales office to ensure we represent the interests of the whole Wales population	• Measures related to the NHSE relationships • Measures related to border Health Boards • Measures related to service reviews

12. Strategic Objectives and Measures of Success

Strategic Aim 4. To be an effective partner, supporting service and system transformation		
Why is this Important? We work on behalf of the 7 Health Boards in Wales and we need to work effectively and transparently with the NHS in both Wales and England to provide excellent services for the whole of the Welsh population.		
Strategic Objectives	**How will we do this?**	**How will we measure success?**
4.3 To ensure a whole system approach to pathway management to reduce unintended consequences	We will work in partnership with health boards and clinical networks to improve standardisation across patient pathways, in line with NICE and GIRFT recommendations We will connect with our wider stakeholders, including the third sector, to align patient pathway development to national approaches	• Measures related to pathway development • Measures related to partnership engagement

12. Strategic Objectives and Measures of Success

Strategic Aim 5. To maximise value and outcomes within available resources		
Why is this Important? We deploy a significant amount of public resources on behalf of the Welsh NHS, in a continuously constrained financial environment. Ensuring value for money and improved outcomes for patients is an important motivation for us in all of our work.		
Strategic Objectives	**How will we do this?**	**How will we measure success?**
5.1 To maximise the use of core resources by recommissioning services where necessary	We will have a systematic recommissioning programme in place, driven by quality, outcomes and value for money, as laid out in our Commissioning Framework All investments will include a clear benefits realisation plan and will be reported to Management Group no later than 3-years post-investment	• Measures related to service reviews • Measures related to benefits realisation
5.2 To focus on improving strategic, service and patient outcomes	Patient outcomes will be one of the key drivers of commissioning, as well as population health and value-based healthcare All new service specifications will include the appropriate service and patient outcome measures and these will be used to shape our commissioning decisions	• Measures related to the collection of PROMS and PREMS • Measures related to Service Improvement and Innovation Days
5.3 To achieve the greatest value for money for the Welsh population	The Integrated Commissioning Plan including the financial plan each year will include contracting and activity assumptions based on clear demand/capacity plans, benchmarking and value for money We will have clear SLAs with all our providers that are managed through our Performance Management Framework and improvement action taken where there is persistent poor performance Value for money in commissioning includes measures to invest in the foundational economy in Wales	• Measures related to contract performance • Measures related to investment in Wales/out of Wales

13. APPENDICES

Appendix 1 –

WHSSC Commissioned Services

Cancer and Blood Services	
• All Wales Lymphoma Panel • All Wales Medical Genomics Service • Brachytherapy • Burns and Plastics • CAR-T therapy • ECMO • Extra corporeal photopheresis • Haematopoietic Stem Cell Transplantation • Hepato Cellular Carcinoma (HCC) MDT • Hepatobiliary Surgery Cardiff • Hepato-Biliary-Pancreatic surgery • Hepatocellular Carcinoma MDT • Hereditary Anaemias specialist service • Hyperthermic Intraperitoneal Chemotherapy (HIPEC) for Pseudomyxoma Peritonei • Immunology • Immunology for Primary Immuno Deficiency	• Long Term Ventilation • Mesothelioma MDT • Microwave ablation for liver cancer • Molecular Radio Therapy • Pancreatic Surgery Morriston • Peptide Receptor Radionuclide Therapy (PRRT) for Neuroendocrine Tumours • PET scanning • Proton Beam Therapy • Radiofrequency Ablation for Barrett's Oesophagus • Specialist MDT for Soft Tissue and Bone Sarcoma • Specialist service for Neuroendocrine Tumours • Specialist service for Paroxysmal Nocturnal Haemoglobinuria • Stereotactic Ablative Body Radiotherapy • Swan Clinic • Thoracic surgery • Welsh Blood Service

Appendix 1 –

WHSSC Commissioned Services

Cardiac Services	
• Heart Transplantation including VAD's • Electrophysiology, ablation and complex ablation • Complex Cardiac devices • Interventional Cardiology, (PPCI, PCI, PFO closures, TAVI, PMVLR) • Inherited Cardiac Conditions • Adult Congenital Heart Disease • Cardiac Surgery • Heart Transplantation including VAD's • Electrophysiology, ablation and complex ablation	• Complex Cardiac devices • Inherited Cardiac Conditions • Adult Congenital Heart Disease • Pulmonary Hypertension • Cystic Fibrosis • Cardiac Networks (SWSWCHD Network, NWNWCHD Network, All Wales Cardiac Network) • Bariatric Surgery • Heart Transplantation including VAD's

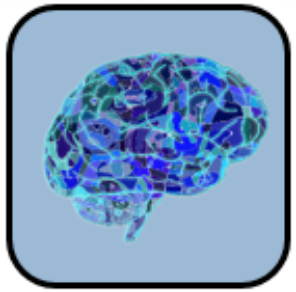
Appendix 1 –

WHSSC Commissioned Services

Mental Health & Vulnerable Groups	
• All Wales Traumatic Stress Quality Improvement Initiative (Traumatic Stress Wales) • CAMHS (Child and Adolescent Mental Health Services) Tier 4 • Forensic Adolescent Consultation and Treatment Service (FACTS) • Gambling • Gender Identity Development Service for Children and Young People • Gender Identity Services for Adults	• High Secure Psychiatric Services • Medium Secure Psychiatric Services • Mental Health Services for Deaf People (Tier 4) • Neuropsychiatry • Specialised Perinatal Services • Specialised Eating Disorder Services (Tier 4)

Appendix 1 –

WHSSC Commissioned Services



Neurosciences Services	
• Alternative Augmentative Communication (AAC) • Artificial Limbs and Appliances Service including • Cochlear and BAHA • Electronic assistive technology • Inherited White Matter Disorders • Neuroradiology (diagnostic and interventional undertaken by neuro-radiologists) • Neurorehabilitation	• Neurosciences • Orbital prosthetics • Prosthetics • Rare Diseases – RDIG • Spinal • Spinal rehabilitation • Wheelchair and special seating

Appendix 1 –

WHSSC Commissioned Services

Women and Children's Services	
• Fertility • Fetal Cardiology • Fetal Medicine • Neonatal • Neonatal Transport • Paediatric Cardiology • Paediatric Cardiac Surgery • Paediatric Cystic Fibrosis • Paediatric Endocrinology • Paediatric ENT • Paediatric Gastroenterology • Paediatric Intensive Care • Paediatric Immunology	• Paediatric Inherited Metabolic Disease • Paediatric Nephrology • Paediatric Neurology • Paediatric Neuro-rehab • Paediatric Oncology • Paediatric Radiology • Paediatric Radiotherapy • Paediatric Rheumatology • Paediatric Surgery • Paediatric Orthopaedic Surgery • Paediatric Infectious Diseases • Perinatal Pathology

Appendix 1 –

WHSSC Commissioned Services

Cross Commissioning Areas
• Intestinal Failure • Home Parental Nutrition • Hyperbaric Oxygen Therapy • Inherited Metabolic Disorder

Appendix 2 - The PESTLE Analysis

Political	Economic	Social
Government policies beneficial/detrimental to WHSSCs success. Is the political environment stable or likely to change?	Economic factors that will impact on us moving forward. Is current economic performance affecting WHSSC? Any impact on our revenue/costs?	How does human behaviour or cultural trends play a role in WHSSC?
• Welsh Government policy and legislation (Wellbeing of Future Generations (Wales) Act, a Healthier Wales: Long Term Plan for Health and Social Care (2021), the Health and Social Care (Quality and Engagement) (Wales) Act (2020), The Foundational Economy in Health and Social Care Strategy (Wales) (2021), Is Wales Fairer? (2018), NHS Quality & Safety Framework (Wales) (2021) • Wales has remained relatively stable politically (Welsh Elections not until May 2026) and uncertainty caused by Brexit and UK General Election December 2022 has now worked through. • The National Clinical Framework (Wales) (2021) will determine how clinical services should develop across Wales, underpinned by a suite of Quality Statements which will provide the next level of detail for specific clinical services. • System changes in the wider NHS such as the establishment of Integrated Care Boards and Integrated Care Systems in England will take on delegated responsibility from April 2023, where appropriate, for specialised services. • The Duty of Candour (Wales) 2023 and the Citizen Voice Body (Wales) 2023, will change the status of equality and human rights and will impact on all public bodies in Wales to be open and honest with service users receiving care and treatment. • Establishment of NHS Executive which will operate under a direct mandate from Welsh Government.	• Economic trend for austerity and spending cuts across public services exacerbating Wales' economic difficulties and impact upon funding settlements. • Lack of investment in capital infrastructure to improve and redesign NHS estates and facilities. • Welsh Government economic policy (Prosperity for all: economic action plan; prudent healthcare) and uncertain WG funding allocation for FE/HEIs in Wales and to meet the increasing funding demands for future social care. • Impact of Health Board funding allocations on WHSSCs funding levels. • Impact of economic and social environment on health inequalities.	• Increasing pressures from a growing and ageing population with more complex health needs; an ageing workforce and generating pressures on workforce and increasing demand on services in a time of austerity and spending cuts. • Health trends such as mental health, obesity and smoking related illnesses. • Post Covid-19 workforce challenges and increasing pressures on staff due to rising demand for health and social care services • Impact on mental health as a result of the Covid-19 pandemic • Trends such as heavy workload, balancing career and personal responsibilities and health resulting in measures to offer more flexible approaches to work and careers for a better work-life balance (part time, portfolio work). • Healthcare inequalities i.e. health provision for children and young people, learning disability. • Urban/rural geography of Wales resulting in hard to recruit areas to maintain sustainable services. • Impact of different levels of Digital literacy (how to use digital functions and use it properly) is variable amongst different age groups.

Appendix 2 - The PESTLE Analysis

Technological	Legal	Environmental
What innovation and technological advancements are available or on the horizon? How will this affect our operations?	What regulation and laws apply to our business? Do they help/hinder WHSSC. Do we understand the laws across WHSSC?	What are the effects of our geographic location? Are we prepared for future environmental targets?
• *Topol Review* support the aims of the NHS long term plan and the workforce implementation plan (i.e. creating a digitally ready workforce ready to use new technology and medicines and to adapt to new ways of working). • Technological advances to provide quality and speedy healthcare through access to digital services • Continuing medical advances in technology (AI, Genomics, digital medicine, robotics) will require changes to the education and training of the workforce. • Changes within technology and communications infrastructure will require a change in roles and functions of clinical staff. • Digital solutions to analyse data, improve intelligence.	• A Healthier Wales: Long Term Plan for Health and Social Care (2021). • Well-being of Future Generations (Wales) Act 2015. • The Health and Social Care (Quality and Engagement) (Wales) Act (2020). • The Foundational Economy in Health and Social Care Strategy (Wales) (2021). • The National Clinical Framework (Wales) (2021). • NHS Quality & Safety Framework (Wales) (2021). • The Duty of Candour (Wales) 2023. • The Citizen Voice Body (Wales) 2023 • Equality Act (2010). • Welsh Language (Wales) Measure 2011.	• Climate Change Act 2008 to reduce carbon emissions, a key contributor to the causes of climate change (50% reduction by 2025 and 80% by 2050) • The Environment (Wales) Act 2016 introduced a duty on Welsh Government to develop carbon budgets for Wales, and to reduce emissions by at least 80% by 2050. • Welsh Government Net Zero Strategic Plan 2022 set out a net zero target for 2050 • The Environment (Wales) Act 2016 requires the government to reduce emissions by at least 80% by 2050. • Increase the amount of renewable energy used, limit emissions from transport, agriculture, industry and business. • Wellbeing of Future Generations (Wales) Act 2015 seeks to reduce our environmental impact in line with the meaning that we are low carbon and efficient with our resources. • Introduction of OFGEM DCP228 will mean a rise in energy costs.

Report Title	**Chair's Report**	**Agenda Item**	3.1
Meeting Title	**Joint Committee**	**Meeting Date**	16/05/2023
FOI Status	Public		
Author (Job title)	Chair of WHSSC		
Executive Lead (Job title)	Committee Secretary and Head of Corporate Services		

Purpose of the Report	The purpose of this report is to provide Joint Committee members with an update of the issues considered by the Chair since the last Joint Committee meeting.				
Specific Action Required	RATIFY ☒	APPROVE ☐	SUPPORT ☐	ASSURE ☐	INFORM ☒

Recommendation(s)

Members are asked to:

- **Note** the report; and
- **Ratify** the Chair's action taken on 9 May 2023 to extend the tenure of Professor Ceri Phillips, Independent Member (IM), WHSSC from 31 May 2023 until 30 June 2023.

CHAIR'S REPORT

1.0 SITUATION

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

2.0 BACKGROUND

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

3.0 ASSESSMENT

3.1 Chair's Action

A Chair's Action was taken on 9 May 2023 to extend the tenure of Professor Ceri Phillips, Independent Member (IM), WHSSC from 31 May 2023 until 30 June 2023.

On the 13 July 2021 the Joint Committee ratified Chair's action taken on 12 May 2021 to appoint Professor Phillips, Vice Chair of Cardiff and Vale UHB, as an IM of the Joint Committee, with effect from 1 June 2021 for an initial term of two years, in accordance with the Welsh Health Specialised Services Committee (Wales) Regulations 2009 and the WHSSC Standing Orders (SOs).

The letter is presented at ***Appendix 1*** for information.

3.2 WHSSC Independent Member (IM) Recruitment

On 18 January 2022 the Joint Committee agreed to 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 existing arrangements for appointing a CTM audit lead IM, can 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; and remunerate WHSSC IMs including the requirement for a review following the recruitment process.

In accordance with the Joint Committees decision to transition to a fair and open selection process for appointing all WHSSC IMs through advertising the vacancies through the HB Chairs and the Board Secretaries, a recruitment process for the third WHSSC IM position will open in May 2023.

3.3 WG Review of National Commissioning Functions

On 20 January 2023, the Director General/NHS Wales Chief Executive wrote to WHSSC advising that the Minister for Health & Social Services had approved a review of the national commissioning functions. This was a commitment within A Healthier Wales and forms part of a set of actions to strengthen and streamline the NHS landscape in Wales. The terms of reference were shared and discussed at the NHS Wales Leadership Board on 24 January 2023.

WG have requested that a facilitated discussion is held with Joint Committee members and a joint workshop took place on 14 March 2023 to coincide with the EASC and WHSSC meetings scheduled for that day.

3.4 Key Meetings

I have attended the following meetings:

- Regular catch up meetings with WHSSC IMs and WKN Chair,
- Regular bi-monthly meetings with the Chair of the QPS Committee,
- Integrated Governance Committee,
- Facilitated discussion with NHS Wales Chairs and Steve Combe on WG review of national commissioning functions,
- NHS Wales Chairs Peer Group Meeting.

4.0 RECOMMENDATIONS

Members are asked to:

- **Note** the report; and
- **Ratify** the Chair's action taken on 9 May 2023 to extend the tenure of Professor Ceri Phillips, Independent Member (IM), WHSSC from 31 May 2023 until 30 June 2023.

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

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

Your ref/eich cyf:
Our ref/ein cyf: KE.JE
Date/dyddiad: 10 May 2023
Tel/ffôn: 01443 443 443 ext. 8131
Email/ebost: Jacqueline.Evans8@wales.nhs.uk

WHSSC Joint Committee Members,

Dear Colleague,

Re: Chairs Action - Extension of WHSSC Independent Member (IM) – 1 Month

I am writing to you to inform you that a Chair's action has been undertaken to extend the tenure of Professor Ceri Phillips, Independent Member (IM), WHSSC from 31 May 2023 until 30 June 2023.

On the 13 July 2021 the Joint Committee ratified Chair's action taken on 12 May 2021 to appoint Professor Phillips, Vice Chair of Cardiff and Vale UHB, as an IM of the Joint Committee, with effect from 1 June 2021 for an initial term of two years, in accordance with the Welsh Health Specialised Services Committee (Wales) Regulations 2009 and the WHSSC Standing Orders (SO's).

The two year period will elapse on the 31 May 2023, and as Professor Phillips has indicated that he intends to stand down at that time, with his agreement, in order to ensure business continuity Chair's action has been taken to extend the time period until 30 June 2023. This is in accordance with the WHSSC SOs which stipulate that:

> *1.4.2 The Vice-Chair and two other Independent Members shall be appointed by the Joint Committee from existing Independent Members of the seven Local Health Boards for a period of no longer than two years in any one term. These members may be reappointed but may not serve a total period of more than 4 years, in line with that individual's term of office on any LHB Board.*

In accordance with the Joint Committee's decision made on the 18 January 2021 to transition to a fair and open selection process for appointing all WHSSC IMs through advertising the vacancies through the HB Chairs and the Board Secretaries, a recruitment process for the third WHSSC IM position will open in May 2023 and expressions of interest will be sought.

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

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

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

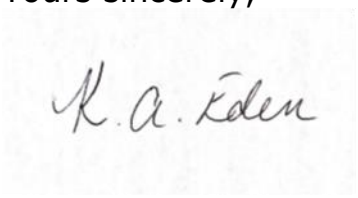
Chair's Action

I confirm that by this letter, acting in conjunction with Dr Sian Lewis, Managing Director of WHSSC, and Steve Spill, Independent Member (IM) of WHSSC, I have taken Chair's Action to approve the extension of Professor Ceri Phillips' tenure as WHSSC IM until the end of June 2023.

This matter will be reported on at the next Joint Committee meeting on the 16 May 2023 for ratification.

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

Yours sincerely,



Kate Eden
Chair

Cc – Dr Sian Lewis, Managing Director, WHSSC
Cc – Stuart Davies, Director of Finance, WHSSC

Report Title	**Managing Director's Report**	**Agenda Item**	3.2
Meeting Title	**Joint Committee**	**Meeting Date**	16/05/2023
FOI Status	Public		
Author (Job title)	Managing Director, Specialised And Tertiary Services Commissioning, NHS Wales		
Executive Lead (Job title)	Managing Director, Specialised And Tertiary Services Commissioning		

Purpose of the Report	The purpose of this report is to provide the Joint Committee with an update on key issues that have arisen since the last meeting.				
Specific Action Required	RATIFY ☐	APPROVE ☐	SUPPORT ☐	ASSURE ☒	INFORM ☒

Recommendation(s):

Members are asked to:

- **Note** the report

MANAGING DIRECTOR'S REPORT

1.0 SITUATION

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

2.0 BACKGROUND

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

3.0 ASSESSMENT

3.1 Single Commissioner for Mental Health

Further to the Joint Committee meeting on 10 January 2023, when six of the seven Health Boards (HBs) on the Joint Committee supported a recommendation to Welsh Government (WG) that WHSSC should be the single commissioner for secure Mental Health service in Wales, on the 20 March 2023 WHSSC received confirmation from WG that they accepted the recommendation. The letter is presented at ***Appendix 1*** for information. I have subsequently written to Welsh Government requesting funding for project management support for the associate programme of work.

3.2 Sacral Nerve Stimulation (SNS) for faecal incontinence in South Wales

A letter from Alex Howells in her capacity as Chair of the NHS Wales Health Collaborative Executive Group (CEG) formally requesting that WHSSC take on the commissioning of Sacral Nerve Stimulation (SNS) for faecal incontinence in South Wales is presented at ***Appendix 2***.

The WHSSC Team will now undertake an evidence review of the procedure, an estimation of demand and budget impact to feed into the WHSSC Integrated Commissioning Plan. A report outlining the process and timeline, will be brought to the July Joint Committee.

3.3 Spinal Operational Delivery Network (ODN)

Following highlighting the delay in the March 2023 meeting it has been confirmed by the Implementation Board that the plan is for the ODN to go live in September 2023.

3.4 Thoracic Surgical Centre Update

Following further detailed capital planning work undertaken by SBUHB as the host provider of the future single Thoracic Surgical Centre a briefing has been received with a more detailed timeline for the delivery of the scheme. At the Project Board meeting in November 2022 an initial indicative timeline was reported that the Centre will be operational during 2026. However the more detailed timeline is now as follows:

Task	Indicative Dates
OBC process and internal endorsement	June 2023 – May 2024
OBC approval by WG	July – August 2024
FBC process (will overlap with OBC) and internal endorsement	March 2024 – March 2025
FBC approval by WG / Appoint SCP/ Enter Contract	April – August 2025
Main works – 2 years	August 2025 – August 2027
Handover and Commissioning of the new build	October 2027

Both the thoracics scheme and the provision of the new access route are contingent upon capital funding and the Joint Committee will be updated on the risks and progress of the planning as required.

3.5 All Wales IPFR Policy Review

The final draft of the All Wales Individual Patient Funding Panel (IPFR) Policy will be presented to the Joint Committee in July 2023. It has not been possible to complete the work in time for the May committee meeting because of the availability of the KC to consider the draft which has now been agreed by WHSSC and stakeholders.

4.0 RECOMMENDATIONS

Members are asked to:

- **Note** the report.

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

Y Grŵp Iechyd a Gwasanaethau Cymdeithasol
Health and Social Services Group

Llywodraeth Cymru
Welsh Government

To: Dr Sian Lewis, Managing Director, WHSSC

Cc: David Roberts, WHSSC
Jon Lane and Sally Thompson, Welsh Government.

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

20 March 2023

Dear Sian

Re: Single Commissioner for Secure Services for Mental Health

Thank you for your recent letter dated 31 January 2023 and our subsequent discussion regarding the recommendation in the Secure Services Review for a single commission for secure mental health services.

Follow review by the Joint Committee, you have confirmed that six of the seven Health Boards (HBs) supported WHSSC as the single commissioner with one HB raising concerns regarding the need for a single commissioner. In your letter, you also included an acknowledgment that the feedback from health boards outlined several areas that would need to be addressed to ensure successful implementation, with recommendations to the Welsh Government.

I am writing to confirm that Welsh Government accept these recommendations and note that WHSSC will now develop a project plan and timeline for the implementation of the new commissioning arrangements.

I would also be grateful if updates are also included within your monthly WHSSC updates.

Yours sincerely

Matt Downton
Head Mental Health and Vulnerable Groups Division,
Welsh Government

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

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

BUDDSODDWYR MEWN POBL | INVESTORS IN PEOPLE

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GIG CYMRU NHS WALES
Addysg a Gwella Iechyd Cymru (AaGIC)
Health Education and Improvement Wales (HEIW)

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Tŷ Dysgu, Cefn Coed,
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Ffôn | Tel: 03300 585 005
Ebost | Email: heiw@wales.nhs.uk
Gwefan | Web: aagic.gig.cymru / heiw.nhs.wales

Our Ref: AH/th

Date: 21 March 2023

Dr Sian Lewis
Managing Director
Welsh Health Specialised Services
Sian.Lewis100@wales.nhs.uk

Dear Sian

I am writing in my capacity as the Chair of the NHS Wales Health Collaborative Executive Group (CEG), to formally request that WHSSC take on the commissioning of Sacral Nerve Stimulation (SNS) for faecal incontinence in South Wales.

As you may be aware, Cardiff and Vale is the only Health Board in Wales that fulfils the requirements set out in the NICE interventional procedure guidance (IPG 99) for delivering SNS for faecal incontinence, and has been providing these procedures for its own residents for the last three years.

Whilst the service has treated a small number of patients from other Health Boards via IPFR arrangements in the past, there are no formal commissioning arrangements in place, and it is currently not able to accept referrals. As a consequence, patients from other Health Boards are being referred to Bristol and Oxford for this procedure. This requires patients to travel long distances, which can be highly challenging for them given the nature of the problem. Patients in North Wales are being referred along an established pathway to Liverpool.

The Welsh Government Quality Statement for women and girls' health (https://www.gov.wales/quality-statement-women-and-girls-health-html) states that "Health boards will ensure that evidence-based surgical techniques and therapies are available without delay throughout the care pathway. This will include effective use of specialist Women's physiotherapy and Sacral Nerve Stimulation in the treatment of bladder and bowel conditions."

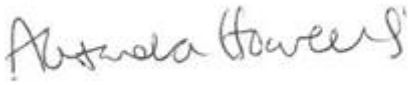
However, in the absence of a NHS Wales commissioning strategy for this highly effective procedure, access for patients in South and West Wales is inequitable, and almost inaccessible for patients who live outside of Cardiff and Vale.

Suzanne Rankin (Chief Executive, Cardiff and Vale UHB) presented a paper (attached) outlining the current position to members at the January meeting of the NHS Wales Health Collaborative Executive Group meeting. Following discussion, the group agreed that the responsibility for commissioning SNS for faecal incontinence should be delegated to WHSSC from 2024/25 onwards.

I would be grateful if the WHSSC team could consider the inclusion of SNS for faecal incontinence within their commissioning intentions for 2024/25.

Please let me know if you have any queries, I look forward to hearing from you.

Yours sincerely



ALEXANDRA HOWELLS
CHAIR - NHS WALES HEALTH COLLABORATIVE

Enc.

c.c. Kate Eden, Chair, WHSSC

Sacral Nerve Stimulation

Author: Ian Langfield, Associate Programme Director for Tertiary and Specialist Services Planning Partnership, Cardiff and Vale University Health Board/Swansea Bay University Health Board

Mrs Julie Cornish, Consultant General Surgeon, Cardiff and Vale University Health Board

Date: 17 November 2022	**Version:** 0.1

Purpose and Summary of Document:

This paper sets out:

- An assessment of current service provision and commissioning arrangements.
- Proposals to inform the future delivery and commissioning of Sacral Nerve Stimulation.

The Collaborative Executive Group is invited to:

- **Note** the content of this report
- **Advise** on the commissioning of Sacral Nerve Stimulation for 2023/24, and to consider delegating responsibility to WHSSC from 2024/25 onwards.

1 Situation

Cardiff and Vale UHB (CVUHB) currently provide the only sacral nerve stimulation service (SNS) in South and West Wales.

The service has been established for 3 years for patients with faecal incontinence in CVUHB, and soon to be expanded to bladder incontinence patients. This procedure is substantially less invasive than current surgical treatments and has been shown to be a cost-effective treatment option.

However, there are no formal commissioning in place for patients in NHS Wales, which means that the service is not able to accept referrals from other Health Boards.

This paper summarises the current issues in service delivery across South Wales, West Wales and South Powys, and proposes the establishment of formal commissioning arrangements for SNS for faecal incontinence.

2 Background

Faecal incontinence is a dysfunction of the bowel and pelvic floor. It affects an estimated 2% of the population, and although it is non-fatal, it is an extremely debilitating condition that significantly impacts patient's quality of life.

Whilst sphincteroplasty is an option for patients in which faecal incontinence is related to external anal sphincter defect, the results deteriorate over time and many patients have a re-occurrence of their symptoms. Other surgical options are invasive and associated with high morbidity and failure rates. Evidence shows that SNS may be used in patients with and without sphincter injury, and that the addition of sphincter repair has little benefit for most patients.

SNS therapy uses mild electrical impulses to stimulate sacral nerves to restore normal bowel function in patients who are refractory to conservative management techniques. This procedure is substantially less invasive than current surgical treatments and has been shown to be a cost-effective treatment option.

National Institute of Health and Care Excellence (NICE) have issued Interventional Procedures Guidance on the use of SNS (NICE, 2004), which states that the evidence on the safety and efficacy of SNS for FI appears adequate to support the use of SNS. A NICE guideline on management of FI in adults (NICE, 2007) states that SNS should be offered to people with FI in whom sphincter surgery is deemed inappropriate (either people with an intact anal sphincter, or those in whom sphincter surgery is contraindicated), and only after a successful trial stimulation period.

Health Technology Wales have concluded that whilst it is difficult to appraise of the cost effectiveness of SNS within the NHS, the general consensus within the literature is that it offers an increased quality of life for patients for a moderate increase in NHS costs.

In the absence of this procedure, some patients will opt for surgery to create a stoma because of the problems caused by severe faecal incontinence. The cost of the surgical procedure and life-long stoma care far exceeds the expense of providing SNS in these patients. Rectal irrigation is a non-surgical option which may be offered to patients but can cost around £1500-2000 per annum on a recurring basis as well as being something that many patients find difficult or unpleasant to do.

3 Assessment

NICE has published interventional procedure guidance (IPG 99) on SNS for faecal incontinence, which states that the procedure "should only be performed in specialist units by clinicians with a particular interest in the assessment and treatment of faecal incontinence".

Cardiff and Vale is currently the only Health Board in Wales that fulfils these requirements, and has been providing these procedures for its own residents for the last three years. Whilst the service has treated a small number of patients from other Health Boards via IPFR arrangements in the past, there are no formal commissioning arrangements in place, and it is currently not able to accept referrals. As a consequence, patients are being referred to Bristol and Oxford for SNS. This requires patients to travel long distances, which can be highly challenging for them given the nature of the problem.

Since 2019, the service has undertaken 14 procedures with permanent SNS, all of whom had temporary SNS trials beforehand. 13 of these patients continue to have successful outcomes. Activity dropped off during the pandemic, but has now picked up and the backlog has been removed.

There are a further 6 patients awaiting surgery.

In NHS Wales there is no commissioning strategy to inform the delivery of this service. In England, complex surgical interventions for faecal incontinence, including SNS, are commissioned by NHS England from Specialist Colorectal Surgery Centres. Similar clinical arrangements exist in NHS Scotland (6 active units/100 permanent procedures per annum) and NHS Northern Ireland (2 active units/25 permanent procedures per annum).

Cardiff is in the process of accreditation from the Pelvic Floor Society for the delivery of PF services and also registering with the UK neuromodulation database. It is recognised on a UK wide basis as being a centre of excellence

for pelvic floor services and the Pelvic Health Hub initiative has attracted interest in visitors both nationally and internationally.

Key Issues

As a consequence, access to this highly effective procedure is inequitable, and almost inaccessible for patients who live outside of Cardiff and Vale.

The surgical team in Cardiff and Vale are keen to develop this service, and to ensure that patients across South and West Wales can have equitable access to this highly effective treatment. Patients in North Wales are being referred along an established pathway to Liverpool.

Following discussion at the Cardiff and Vale Tertiary Service Oversight Group, it was recognised that this service is specialised service which would benefit from a consistent commissioning approach. The Health Board has written to the WHSSC Managing Director to formally request that the SNS Service for the treatment of patients with Faecal Incontinence is considered for inclusion as part of the WHSSC commissioning intentions for 2024/25.

The WHSSC Managing Director has responded to confirm that the service was previously considered for commissioning by WHSSC in 2018, but at that time it was considered that the service should be commissioned by health board, because of the overlap and interdependencies with existing colorectal services. They have suggested that the issue is discussed with the Collaborative Executive Group, and if that there is support for delegating the commissioning responsibility to WHSSC, a formal request is submitted by the Chair.

However, even if this service is included within the WHSSC commissioning intentions for 2024/25, it would still remain unavailable for patients in Wales for the remainder of 2022/23 and all of 2023/24.

4 Recommendations

It is recommended that:

- Consideration is given to formally delegating responsibility for commissioning SNS for faecal incontinence to WHSSC from 2024/25 onwards; and that
- Interim commissioning arrangements for SNS are established with the five Health Boards in South and West Wales, to ensure that all patients have timely and equitable access to this effective treatment.

5 Decision required

The Collaborative Executive Group is invited to:

- **Note** the content of this report.
- **Advise** on the commissioning of Sacral Nerve Stimulation for 2023/24, and to consider delegating responsibility to WHSSC from 2024/25 onwards.

Report Title	**Review of Specialised Commissioning in Haematology: Acute Myeloid Leukaemia (AML), Acute Lymphoblastic Leukaemia (ALL) and High Risk Myelodysplasia (HRM)**	**Agenda Item**	3.3
Meeting Title	**Joint Committee**	**Meeting Date**	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 report on Acute Myeloid Leukaemia (AML), Acute Lymphoblastic Leukaemia (ALL) and High Risk Myelodysplasia (HRM) from the review of specialised commissioning in haematology.				
Specific Action Required	RATIFY ☐	APPROVE ☒	SUPPORT ☐	ASSURE ☐	INFORM ☒

Recommendation(s):

Members are asked to:

- **Note** the findings of the specialised haematology review in relation to the opportunities, risks and challenges for the Acute Myeloid Leukaemia (AML), Acute Lymphoblastic Leukaemia (ALL) and High Risk Myelodysplasia (HRM) service in Wales,
- **Consider** the options proposed for how specialised commissioning under WHSSC could address the opportunities, risks and challenges in the AML, ALL and HRM service to provide an equitable, high quality and sustainable service for patients in Wales; and
- **Approve** option 4, the phased implementation of option 1 (all Wales MDT) and option 3 (network service model for Wales), as the preferred option.

REVIEW OF SPECIALISED COMISSIONING IN HAEMATOLOGY: ACUTE MYELOID LEUKAEMIA (AML), ACUTE LYMPHOBLASTIC LEUKAEMIA (ALL) AND HIGH RISK MYELODYSPLASIA (HRM)

1.0 SITUATION

The purpose of this report is to outline the main findings and proposals of the report on Acute Myeloid Leukaemia (AML), Acute Lymphoblastic Leukaemia (ALL) and High Risk Myelodysplasia (HRM) from the review of specialised commissioning in haematology.

WHSSC's Integrated Commissioning Plan (ICP) 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 for AML, ALL and HRM. The full report is contained in ***Appendix 1***. In this cover report, the term AML is used as shorthand to refer to the 3 related conditions AML, ALL and HRM.

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 Blood & Marrow Transplant (BMT) complications arising 100 days or more post transplantation,
- Salvage treatment for patients with 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 (CVUHB), 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. For AML, a further 2 all Wales clinical stakeholder meetings were held in addition to separate meetings with each HB.

3.0 ASSESSMENT

The full AML report is contained in ***Appendix 1*****.** Below is a summary of the opportunities, risks and challenges that are described in detail in the full report. The three potential options identified in the full report for the role of specialised commissioning are then outlined.

3.1 Epidemiology

Acute Myeloid Leukaemia (AML) is a rare blood cancer with an age dependent incidence which markedly rises above the age of 60 years. The median age at diagnosis is 70 years with a slightly higher incidence in men. There are approximately 150 incident cases of AML per annum in Wales. Due to the ageing population, this incidence is increasing.

Survival rates for AML are poor: overall 5 year survival is just 15%. While AML can be potentially cured through intensive chemotherapy (and in some cases BMT), only 30% (approximately) of patients are suitable for this treatment. These tend to be younger patients. The remaining 70% of patients are offered less intensive, palliative treatment.

3.2 Current Pathways

Table 1 summarises where AML diagnostics and treatment currently take place for residents of each HB. CVUHB is the main provider in south Wales. Betsi Cadwaladr UHB (BCUHB) provides the service for the majority of its patients but also draws on support from services in NHS England (NHSE).

Table 1 - Pathways for Diagnosis and Treatment of AML

	Diagnostics and monitoring		Chemotherapy	
UHB	**Immunophenotyping**	**Genetics**	**Intensive with curative intent**	**Less intensive / Palliative**
Aneurin Bevan	Cardiff	Cardiff	Cardiff	Aneurin Bevan
Cardiff & Vale	Cardiff	Cardiff	Cardiff	Cardiff
Cwm Taf Morgannwg	Cardiff	Cardiff	Cardiff	Cardiff
Swansea Bay	Swansea	Cardiff	Swansea	Swansea
Hywel Dda	Cardiff	Cardiff	Cardiff	Hywel Dda
Betsi Cadwaladr	Betsi/Birmingham	Cardiff/Liverpool	Betsi/Manchester	Betsi
Powys	As per treating health board or NHSE Trust	Cardiff	As per treating health board or NHSE Trust	As per treating health board or NHSE Trust

3.3 Opportunities

3.3.1 New treatments

New specific inhibitors are entering routine clinical practice with many more in trials and expected to enter clinical practice over the next 5 to 10 years. Compared with chemotherapy, they have been shown to significantly improve survival/cure rates, have a lower side effect profile and will increase the proportion of AML patients suitable for potentially curative treatment.

Inhibitor therapies can be delivered on an out-patient basis, in contrast to intensive chemotherapy which requires in-patient care. Delivery will therefore require sufficient day unit facilities but will release haematology beds. Whereas intensive chemotherapy takes place in specialist centres, the new inhibitors could in principle be delivered more locally to patients with specialist oversight and monitoring. The net financial impact of these new treatments is uncertain at present.

The potential for release of bed days in specialist centres provides the option for this capacity to be allocated to other services such as new Advanced Therapeutic Medicinal Products (ATMPs)/CAR-T (chimeric antigen receptor T-cell).

3.3.2 Genomics and targeted therapy

AML sub-types are increasingly defined genetically rather than through traditional morphology and immunophenotyping. The new inhibitor therapies are targeted to treat specific genetic sub-types of AML. Since rapid treatment is vital to patient outcome in AML, turnaround times for genomic testing need to be short (new national guidelines coming into effect stipulate within 3 to 4 days for some sub-types). Genetic testing is also becoming, alongside immunophenotyping, important for monitoring response to treatment (measurable residual disease (MRD).

NHS Wales needs to be able to organise service delivery to take advantage of the opportunity presented by the new inhibitor therapies, supported by genomics, to improve outcomes for patients with AML.

3.4 Risks and challenges in the current service

There are a number of significant challenges and risks for the current AML service provision across Wales and also for the ability of the service to capture the patient and system benefits of the new inhibitor therapies. An overview of some of the main issues is provided here (for detail on each service and HB, see full report in A***ppendix 1***).

3.4.1 Access to rapid, high quality diagnostics: immunophenotyping and genomics

Effective AML treatment requires access to rapid diagnostics and monitoring of response to treatment. There are currently risks to the ability to provide this sustainably in Wales.

The laboratory in CVUHB provides the immunophenotyping service for the majority of AML patients in Wales. However, the laboratory lacks the necessary capacity (staff expertise and equipment) to sustainably provide the level of service required (turnaround time > 2 weeks for acute leukaemia). This is an increasing risk exacerbated by expected retirements over the next 12 months which will result in the loss of highly experienced staff. The funding model has not kept pace with the increasing demands of AML diagnostics and monitoring, both in terms of the numbers of patients and the complexity of testing.

Inadequate turnaround time also affects the service in north Wales. Sometimes when fast turnaround is essential, samples are sent to laboratories in England which are able to return results quickly.

Current turnaround times in genetics are also not sufficiently rapid to support optimal clinical decision making. Under new standards being adopted in England, results will need to be available within 7 days or less depending on sub-type. Current turnaround time standards and performance in Wales are significantly longer.

In addition to slow turnaround times, due to capacity constraints, there is currently no immunophenotyping or genetics presence at the AML MDT at CVUHB.

3.4.2 Treatment Capacity

There is recognised to be insufficient haematology bed capacity at the University Hospital of Wales (UHW), which treats the majority of South Wales patients, to provide the optimal level of care for patients receiving intensive chemotherapy regimens. This is a long standing constraint which has not been addressed through the existing commissioning model via HB to HB SLAs. As a consequence, patients are discharged to local care earlier than is clinically optimal and are vulnerable to neutropenia as a result.

As noted above, the new inhibitors have the potential for local delivery in day unit facilities. This requires the identification of suitable facilities in each HB and trained staff (nursing, pharmacy as well as medical) to be able to safely deliver treatment. For example, Aneurin Bevan UHB (ABUHB) while it has much of the staffing infrastructure (notably medical), it does not currently have the day unit capacity to treat patients locally.

3.4.3 Consultant Recruitment and Service Sustainability

There is a significant challenge recruiting to substantive consultant haematology posts in south west Wales (Hywel Dda UHB (HDdUHB) and Swansea Bay UHB (SBUHB)). As a consequence, the service is increasingly dependent on locum haematologists. The dependence on locum consultants may increase as a number of retirements are expected among the current substantive consultant workforce over the next 5 years. This will make it increasingly difficult to provide the shared

care needed for intensive chemotherapy patients and to be able in the near future to support a model of care to treat patients locally with the new inhibitor therapies.

The AML service for SBUHB is currently delivered by a single consultant. This is a clear risk for the sustainability of the service for the population of SBUHB. If the service were to fail, there is no spare capacity at UHW to admit these patients.

North Wales also has challenges with the substantive recruitment of haematologists. The AML service is provided by two substantive consultants supported by two locum consultants. A loss in substantive consultant capacity would mean patients would be referred to England for treatment.

3.4.4 Distribution of medical expertise and capacity

In south Wales, consultant expertise in AML is currently concentrated in the south east (ABUHB – 3 x consultants; CVUHB x 3 consultants) while the service in SBUHB is dependent on a single consultant. The distribution of expertise creates a challenge for ensuring equitable access to a sustainable service across the region. While there is medical expertise in ABUHB, this is not currently being utilised to deliver intensive treatment.

3.4.5 Increasing sub-specialisation and expertise

AML is already highly sub-specialised but this will further increase as the diagnosis of sub-types becomes more complex and treatment options become more varied and complex (depending on genetic sub-type). Therefore, the service model will need to ensure that this clinical expertise is grown and sustained, and that patients have equitable access to this expertise.

3.4.6 Coordinated planning and strategic direction

The risks and challenges outlined here require coordinated planning across HBs to address them. Coordination is needed to address the risks to the sustainability of the service both for diagnostics and treatment, to ensure equitable access to clinical expertise, and to plan effectively for implementing the new genetically targeted inhibitor therapies which require transformation in the delivery model. The net financial impact of these new treatments is uncertain at present.

3.4.7 Health Board (HB) Risk Registers

The review has highlighted a number of significant risks relating to the AML service. HB clinical teams were asked whether AML as a service was included on their risk registers. While a complete response has yet not been obtained, it appears that the AML service is not included on risk registers although broader risks within haematology that will affect AML are reflected. The responses received to date are summarised in ***table 2***.

Table 2 - AML Inclusion on Health Board Risk Registers

Health Board	Is the AML service on the risk register?	Are broader risks relating to haematology on the risk register?
Aneurin Bevan	No	Yes. (day unit space, clinic rooms, bed numbers, nursing numbers)
Betsi Cadwaladr	No	To be confirmed
Cardiff & Vale	Yes (on directorate risk register)	Yes. (incl. consultant vacancies and pharmacy support)
Cwm Taf Morgannwg	To be confirmed	To be confirmed
Hywel Dda	To be confirmed	To be confirmed
Swansea Bay	No	Yes. (workforce constraints in haematology – medical)

3.5 Options for role of specialised commissioning

AML seems appropriate in principle for specialised commissioning. The rarity of AML (150 new case p/a in Wales) meets with the specialised services criterion of small numbers of patients. The high level of medical sub-specialisation required is also consistent with specialised services as delivered from a small number of centres. In addition, the new inhibitor treatments are high cost therapies. Currently commissioning for acute leukaemia is not a designated specialised service in NHSE although haematological cancer care is provided through a cancer network approach on a regional basis.

The current service contains significant risks as described above, including sustainability of medical provision, lack of capacity and slow turnaround in diagnostics, lack of in-patient capacity for delivering treatment, increasing complexity of diagnostics and treatment options, and increasing treatment costs. While a regional service is provided from Cardiff for the majority of South Wales patients, it is not clear that commissioning via HB to HB SLAs is providing the coordinated planning and funding to enable the service to sustainably meet the needs of patients. SBUHB has its own service but this lacks resilience at the current time. BCUHB has centralised the service to concentrate resources and expertise for intensive chemotherapy but capacity is stretched to provide support for all patients (incl. palliative) across the three hospital sites.

The AML report at ***Appendix 1*** proposes the following options (options 1 to 3) for the potential role of specialised services commissioning. See the main report

for a detailed description of these options. Below a 4th option, the phased combination of options 1 and 3, is also proposed.

Option 1: all Wales AML MDT plus immunophenotyping

This option includes a centrally commissioned AML MDT and immunophenotyping (genomics already being under WHSSC's remit but will require additional investment through the strategic expansion being funded centrally by Welsh Government (WG) to achieve new national standard turnaround times) since rapid, high quality diagnostic information is essential to enabling the MDT to make timely decisions. Included within this option is the repatriation to ABUHB of the treatment (intensive chemotherapy/inhibitors) of its AML patients. This option will address some but not all of the opportunities, risks and challenges affecting the service. ***Table 3*** below outlines the benefits of option 1 an All Wales MDT.

Table 3 - Benefits of an all Wales MDT (option1)

Benefits	Opportunities, risks and challenges not addressed
a) Ensures all AML patients get access to expert AML opinion to inform their individual care pathway. b) Brings Welsh immunophenotyping and genetic services into compliance with national and international standards which is not the case at present. c) Ensure patients receive the correct therapy in the timeliest and most cost efficient manner. d) Improves the efficiency of the existing AML MDT by having all necessary results available for discussion in a single MDT meeting. e) Allow patients from ABUHB to be treated locally and relieve CVUHB of having to manage these patients. f) By the AML MDT allowing all ABUHB AML patients to be treated locally, this reduces the pressure on CVUHB resources (in-patient beds, Day Unit etc.) which could possibly enable CVUHB to undertake more BMT and CAR T services, and even offer some support should the AML service in SBUHB become unviable for any reason e.g., single handed consultant not at work for whatever reason.	a) Ensuring appropriate capacity and sustainable provision of intensive chemotherapy at Cardiff for residents HDdUHB, CTMUHB and CVUHB. b) The issues of functionally delivering (and possibly becoming more difficult as consultants retire) the existing and soon to be introduced new inhibitor agents in CTMUHB and HDdUHB due to insufficient specialist nursing, pharmacy support and in places physical facilities. Thus, patients who could be treated nearer to home may still have to travel to Cardiff to safely receive the correct treatment. c) The SBUHB consultant staffing issue (single handed service/challenges of recruitment).

Benefits	Opportunities, risks and challenges not addressed
g) Brings north Wales into a Welsh AML MDT improving communications between Welsh centres.	

Option 2: Option 1 plus central commissioning of CVUHB to manage the care of AML patients in CTMUHB and HDdUHB

In addition to a centrally commissioned all Wales MDT and immunophenotyping service, this option seeks to ensure sufficient capacity for AML treatment (intensive chemotherapy/inhibitors) at Cardiff for residents of HDdUHB, CTMUHB and CVUHB. BCUHB, ABUHB and SBUHB would commission and provide intensive chemotherapy and new inhibitor treatment for their own residents. Table 4 outlines the benefits of an all Wales MDT plus central commissioning of treatment for HDdUHB, CTMUHB and CVUHB.

Table 4 - Benefits of an all Wales MDT plus central commissioning of treatment for HDdUHB, CTMUHB and CVUHB

Benefits	Opportunities, risks and challenges not addressed
In addition to the benefits from option 1: a) Allows CVUHB to strategically plan their AML care pathway better as future funding streams are more secure. b) Allow increased access for patients at CTMUHB and HDdUHB to AML expertise. c) With CVUHB effectively being made more responsible for the AML service within CTMUHB and HDdUHB, there would be expected to be better cooperation, training and knowledge exchange between all levels of staff e.g., nursing, pharmacy etc. d) Lead to less disruption to general on-call haematology arrangements within individual UHBs.	a) Address the issues of functionally delivering (and possibly becoming more difficult as consultants retire) the existing and soon to be introduced new inhibitor agents in CTMUHB and HDdUHB. Thus, patients who could be treated nearer to home may still need to travel to Cardiff to safely receive the correct treatment. b) Address the SBUHB consultant staffing issue (single handed service/challenges of recruitment).

Option 3: AML network model for Wales

This option aims to establish arrangements that facilitate realising the opportunities offered by new inhibitor therapies and addressing the risks and challenges for the AML service across Wales through a centrally commissioned network model. ***Table 5*** outlines the benefits of an AML network model for Wales.

Table 5 - Benefits of an AML Network Model for Wales

Benefits
In addition to the benefits from option 1: a) Ensure Wales has a fit for purpose strategy for AML care and the means to operationally deliver that strategy. b) Would ensure the safe and best functional delivery of AML care to patients in CTMUHB and HDdUHB ideally near to their homes even if consultant numbers reduce further due to retirements. c) Future proof SBUHB in case their haematology consultant vacancies are not filled. d) Ensure general haematologists in HDdUHB and CTMUHB are kept up to date with AML developments and their own patients through the local consultant with protected AML sessions paid for by the AML Network. e) **May** help attract and retain doctors west of Bridgend, as they will be more intimately involved in the care of some of the most clinically demanding (skills wise) but rewarding haematology patients.

Option 4: Phased approach of option 1 (MDT/diagnostics) in the first phase progressing to option 3 (Network model)

Option 4 is comprised of both options 1 and 3 implemented in a two phase approach which would commission the all Wales MDT in phase 1 followed by a second phase to commission the network model. This would enable a number of the risks identified through the review to be addressed through phase 1 while the complex work to develop an operational network model is undertaken for implementation as a second phase to put in place a sustainable operational model for the acute leukaemia service in Wales.

4.0 RECOMMENDATIONS

Members are asked to:

- **Note** the findings of the specialised haematology review in relation to the opportunities, risks and challenges for the Acute Myeloid Leukaemia (AML), Acute Lymphoblastic Leukaemia (ALL) and High Risk Myelodysplasia (HRM) service in Wales,
- **Consider** the options proposed for how specialised commissioning under WHSSC could address the opportunities, risks and challenges in the AML service to provide an equitable, high quality and sustainable service for patients in Wales; and
- **Approve** option 4, the phased implementation of option 1 (all Wales MDT) and option 3 (network service model for Wales), as the preferred option.

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.
Organisational Implications	
Quality, Safety & Patient Experience	The paper describes risks and challenges in the current service for patients with AML.
Finance/Resource Implications	The paper focuses on 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 AML.
Legal Implications	No legal implications have been identified.
Long Term Implications	As new treatments become available, changes in the delivery model for AML will be required to take full advantage of the benefits for patients.
Report History	6 February 2023 – CDGB; 6 March 2023 – represented to CDGB 23 March 2023 – Management Group 2 May 2023- CDGB
Appendices	Appendix 1 - Full Report Findings and Proposals for AML, ALL and HRM

Review of Specialised Commissioning in Haematology and Immunology

Options Paper for possible central commissioning by WHSSC of adult Acute Lymphoblastic Leukaemia, Acute Myeloid Leukaemia and High Risk Myelodysplasia services by WHSSC.

A) Background

Acute myeloid leukaemia (AML) is a rare blood cancer with an age dependent incidence which markedly rises above aged 60 years. The incidence is increasing from 3.48 in 1976 to 5.06 patients per 100 000 people in 2013 (45% increase) probably in part as a result of an increasingly ageing population, so this trend will only continue[1]. Wales therefore has ~150 new adult AML cases per annum. The median age of diagnosis is 70 years with a slightly higher incidence in men. AML is a potentially curable cancer but is rapidly fatal in the absence of appropriate specialist care and treatment. Survival rates are largely determined by the genetic sub-type of AML and age of the patient with overall only 15% 5 year survival[2]:
– 50% 5yr survival age <40

- 45% 5yr survival age40-49

- 25% 5yr survival age 50-59

- 15% 5yr survival age 60-69

- 5% 5yr survival age 70-79

- 2% 5yr survival for the over 80s

Given the poor overall survival rates new (non-chemotherapy) therapies are urgently required and are just starting to become routinely clinically available through NICE guidance.

The cornerstone of treatment for younger patients has been intensive multi-drug chemotherapy which has typically been delivered in specialist centres with in-patient and Day Unit facilities and specialist nursing and pharmacy support. Treatment has traditionally consisted of induction and consolidation chemotherapy with patients typically requiring in-patient support for up to 2-4 months over a 3-6 months period with frequent Day Unit and out-patient visits in between the typical 3-4 courses of intensive chemotherapy. Although

intensive chemotherapy can cure a minority of AML patients, assuming they are fit (typically <60 years of age) and responding to the initial chemotherapy, many go on to receive allogeneic stem cell transplantation to increase cure rates.

Acute Lymphoblastic Leukaemia (ALL) in adults is less common than AML (~5 per million/year ~ 10-12 cases/year in south Wales) and is similarly treated with in-patient chemotherapy for 4-6 months but in ALL outpatient chemotherapy continues for a further 24 months. Long term survival for adults with ALL is 30-40%.

AML and ALL are diagnosed by a combination of morphology, immunophenotyping, conventional karyotyping and more recently molecular (NGS) testing. The pathogenesis of AML has become increasingly understood with very many underlying genetic abnormalities identified. Historically AML had been classified morphologically/immunophenotypically but over the last 20 years this has switched to a genetic classification as new genetic abnormalities were identified. The World Health Organisation (WHO) have just published their 5th classification of AML in which not only do they extend the genetic classification of AML but also highlight the similarities between the underlying pathogenesis (genetic abnormalities) between AML and high risk MDS (HR MDS) indicate that the two conditions should be treated similarly[3]. Not only has the identification of the very many genetic abnormalities underlying AML/ HR MDS allowed improved prognostication and refined tracking of 'measurable residual disease' (MRD) to more accurately monitor response to therapy, they now also direct the choice of therapy as different genetic subgroups respond differentially to drug therapies as the cellular survival pathways influenced by the genetic changes were suitable for the clinical development of new specific pathway inhibitor therapies which are just entering routine clinical practice. Karyotyping and Next Generation Sequencing (NGS) is presently provided by the WHSSC commissioned All Wales Medical Genetics Service (AWMGS) in Cardiff. So, in the last five years, the arrival of new drugs such as Mylotarg, CPX-351, midostaurin etc means that karyotyping for abnormalities such as FLT3/NPM1, CBF (inv16, 8;21) need to be reported within <7 days (ideally <3-4 days) as opposed to the usual 3 weeks its taking AWMSG. Similarly, the turnaround time of <7days will soon be standard (National guidelines in press) for NGS, as opposed to the present 3-6 weeks presently provided by AWMGS as identifying abnormalities such as IDH status, TP53 status etc will direct therapeutic decisions and choice of therapies. For examples, NGS identifies abnormalities which now define whether patients have a particular subtype of AML -- AML with myelodysplasia related changes (AML-MRC with RUNX1, SRSF2 etc genetic abnormalities) - which determines which patients should get the new agent CPX-351 during induction chemotherapy. The key change already impacting AML care is the introduction of venetoclax-based therapies (particularly azacitidine/venetoclax, low dose cytosine arabinoside/venetoclax). This means that a smaller % of borderline fitness cases (in the 55-75 window) will be having intensive therapy, and that those patients (and those who would previously have been having azacitidine monotherapy) will be getting treated at base hospitals. More monitoring required, FBCs, dose adjustments (venetoclax dose and duration, azole interactions), bone marrow monitoring at several timepoints to determine

dose intervals, when to treatment etc. Many of these patients will remain on venetoclax-based therapies for >>6-8 cycles (beyond 18 months in many cases).

Also, as above, this ties in for the need for genetic testing to determine suitability for certain therapies (Mylotarg, CPX, gilteritinib, midostaurin, IDH inhibitors with more to come e.g. Menin inhibitors for the MLL subtype of AML.

Also knowing the full genetic picture allows more nuanced conversation with patients who lie on the borderline between intensive/non-intensive chemotherapy approaches – this is a substantial minority – but the advent of venetoclax-based regimens means there is a meaningful clinically effective alternative to intensive chemotherapy. So although intensive chemotherapy has historically been the mainstay of AML/ HR MDS treatment, the treatment paradigm is already changing and will change quite dramatically over the next 5-10 years with very expensive non-chemotherapy specific inhibitors which have been shown to significantly improve survival entering routine clinical practice for particular genetic subtypes. These new non-chemotherapy agents often have fewer side effects than traditional intensive chemotherapy which may enable older and potentially more patients with co-morbidities to be treated increasing response rates, duration of response and cure across Wales. However, the diminished side effect profile will reduce the need for in-patient beds, but increase the need for suitable Day Unit facilities and mean many more patients will be able to be treated within their local area rather than go to Cardiff as happens at present for the overwhelming majority. However, the side effect profile of these new agents are often very different from chemotherapy and expertise in their safe use across Wales is very limited at present and often only resides in Cardiff.

Both immunophenotyping and molecular testing for both AML, HR MDS and ALL can also be used to assess the response to treatment (MRD) giving clinicians very important information into how effective- or not – the treatment is, enabling better and more efficient use of both traditional chemotherapy, but especially the new specific inhibitors (molecular testing). Given the importance of genetic testing to diagnose, direct treatment and assess response, the British Society for Haematology in conjunction with the national genetic services, are just about to publish new guidelines for their use in AML[4].

B) Present service configuration (general).

i) AML, High Risk MDS (HR MDS) and ALL Diagnosis

The diagnosis of AML, HR MDS and ALL is often suspected by morphological examination of a blood film or bone marrow at the local hospital where the patient presents but confirmation is required by both immunophenotypic and cytogenetic/molecular testing. Immunophenotyping for Wales is mostly provided by the haematology laboratory at the University Hospital of Wales (UHW - Cardiff), although Swansea and north Wales have an in-house service for their own patients, whilst the WHSSC funded All Wales Medical Genetic Service (AWMGS) provides all genetic analyses. The UHW immunophenotyping laboratory is in-house health board funded receiving monies for external work via generic SLAs between

CVUHB and other Welsh UHBs. This has meant that it has not developed in terms of capacity (equipment, staff numbers and expertise) leading to a slow, clinically less than optimal service. Despite the importance of immunophenotyping in the management of both AML, HR MDS and ALL, the immunophenotyping service does not directly attend the UHW AML MDT. Virtually all centres in England, Scotland and Northern Ireland have progressed to issuing a single integrated and comprehensive report containing the patient specific morphological, immunophenotyping and genetic data which forms the cornerstone of the MDT patient pathway decision making process.

ii) Clinical Provision of AML/ HR MDS and ALL services

Once diagnosed with AML/HR MDS or ALL, south Wales patients outside Swansea and Bridgend who are deemed potentially curable are transferred/admitted to the haematology service (beds allowing – only 17 routine – non BMT/CAR-T - beds) at UHW under the care of three (2.0 WTE) AML and two (1.0 WTE) ALL experts. Patients diagnosed in Swansea and Bridgend are treated at Singleton hospital whilst north Wales' patients are admitted to Glan Clwyd with Wrexham Maelor presenting patients given the choice of being admitted to Glan Clwyd or transferring to a hospital in England for their care. Having received their intensive first induction chemotherapy, patients in Swansea and north Wales, along with the rest of the UK, are typically kept as in-patients until marrow recovery but patients at UHW have always had to be discharged either to home or their referring hospital immediately after completion of their induction chemotherapy due to a lack of bed capacity at UHW. This means that the overwhelming majority of patients discharged from UHW will require urgent re-admission for potentially life-threatening neutropenic sepsis either in Cardiff (beds and ambulances allowing) or their local hospital. Between courses of intensive chemotherapy patients require regular assessments (typically at least twice-weekly) at their local hospital Day Unit for blood count/organ (renal, liver, respiratory) monitoring, complications of AML, ALL/chemotherapy, blood and/or platelet transfusions, central line care and disease assessment.

Patients who are not potentially curative are usually managed at the local hospital by the local haematology team. This has historically been somewhat variable with patients from DGHs closer to Cardiff (Prince Charles Hospital, Royal Glamorgan Hospital etc) going to Cardiff for non-intensive therapies such as azacitidine, whilst more distant DGHs have had to deliver non-intensive therapies themselves often with sub-optimal medical, nursing and pharmacy support and physical infrastructure. When clinical trials of first-line non-intensive therapy (eg. AML16, AML LI-1 etc) have been available in Cardiff this has meant that a greater proportion of these non-intensively treated patients have come to Cardiff rather than be treated at their local DGH but in reality this has led to fewer patients in local DGH's being offered the possibility of access to potentially life impacting clinical trials.

So, although CVUHB, via its UHW haematology service, has led the care for the overwhelming majority of AML/HR MDS and ALL patients in south Wales this has been in-house health board funded via the various generic SLAs between CVUHB and other UHBs. As

with immunophenotyping, this has led to a lack of investment of the AML/HR MDS and ALL service across Wales but especially in Cardiff, leading to inadequate in-patient bed and Day Unit capacity at UHW to manage patients especially from outside its own catchment population leading to a less than ideal service for patients and back pressure on local haematologists outside Cardiff. This problem is compounded by UHW not being funded to provide a 24/7 AML/HR MDS and ALL expert advisory service to support local haematologists even for those patients who may have received their intensive chemotherapy in Cardiff.

There are at present 7 haematology consultant vacancies across Wales and the reality is that there has not been a substantive haematology consultant post filled in the last 8 years west of Bridgend in south Wales despite these vacancies and this continues to impact the capacity to locally deliver AML/HR MDS and ALL care. This situation is expected to significantly worsen in the next 3-5 years with the retirement of up to 4 consultant posts west of Bridgend.

C) Present service configuration – specific UHB issues (alphabetical).

1) Aneurin Bevan University Health Board

Meeting held 26th July 2022 and written comments also received. Attendees: Dr Chris Jenkins, Dr Ali Mahdi, Dr Eamon Mahdi. Feedback/final thoughts meeting 25/11/22 – attendee Dr Victoria Williams.

ABUHB presently sees 20-25 new acute leukaemia patients/year and has 2.6 specialist myeloid acute leukaemia consultants. Initial acute leukaemia diagnosis is suspected based on a morphological assessment of peripheral blood (and sometimes bone marrow) undertaken within ABUHB. If patients are fit and at present able to tolerate intensive chemotherapy are referred to an AML/HR MDS or ALL specialist at UHW and receive their induction chemotherapy at UHW. Patients deemed unsuitable for intensive therapy are managed at ABUHB (8-11 in-patient beds in total for all haematological disorders) where a bone marrow will be undertaken with samples sent through to UHW for AML/HR MDS and ALL immunophenotpying and AWMGS service. ABUHB deliver non-intensive therapy although this is not always easy as Haematology does not have its own Day Unit facility and although it shares a Day Unit with other specialties Haematology does not have access to that Day Unit every day and have inadequate CNS support which leads to inefficiency and difficulty in delivering some treatments including some of the new AML therapies such as outpatient venetoclax/azacitidine and clinical trials.

The consultant however would like look after all acute leukaemias in ABUHB on-site but this will require increased CNS support, at least 5 day/week access to a Day Unit, increased R&D input and the support of an expert led and fully functional all-Wales acute leukaemia MDT. Even if ABUHB doesn't take on the management of young fit AML/HR MDS and ALL patients (for in-patient intensive chemotherapy) they will still need more Day Unit/CNS support and

a national AML MDT to safely offer the new specific inhibitor therapies entering clinical practice.

The consultants at ABUHB did not see any great advantages of an AML network model assuming a centrally commissioned fully functional acute leukaemia MDT is in place.

ABUHB does not undertake any immunophenotyping or genetic laboratory AML/HR MDS and ALL services but expressed concerns about the timeliness of both of the present services provided by UHW and the AWMSG.

2) Betsi Cadwaladr University Health Board

Meeting held 9th August 2022. Attendee Dr Ernest Heartin. Feedback/final thoughts meeting 25/11/22 – attendee Dr Ernest Heartin.

The AML/HR MDS and ALL service at BCUHB is centred around the North Wales Cancer Treatment Centre based at Glan Clwyd Hospital in Rhyl accepting patients from both Bangor and Wrexham Maelor hospitals although at the latter the patients are also given the option to be treated at an English hospital. The in-patient AML/HR MDS and ALL service is managed by 2.0 WTE haematology consultants (including Dr Heartin) who provide a complete morphological, diagnostic and prognostic work up with all patients treated within BCUHB. Diagnostic immunophenotyping samples are sent to their own in-house immunophenotyping service and/or to Dr Freeman's laboratory in Birmingham who offer a much speedier (24-48 hours) and deeper analysis (including MRD) which the BCUHB immunophenotyping service is at present unable offer. Genetic samples are always sent to the AWMSG in Cardiff but duplicate samples may also be sent to Liverpool who provide a result within 72 hours compared to the many weeks presently being taken by the AWMGS. All AML/HR MDS and ALL patients are discussed with the MDT at the Christie Hospital (Manchester) which if appropriate is where patients who respond and achieve complete remission will ultimately be sent for allogeneic transplantation. Patients are admitted for the complete course of their induction and subsequent chemotherapy and upon discharge jointly cared with haematologists in Wrexham and Bangor in their Day Unit facilities. BCUHB is able to offer their AML/HR MDS and ALL patients access to clinical trials.

The main issues within the BCUHB AML/HR MDS and ALL service is a shortage of specialist AML/HR MDS and ALL CNSs and the reality that the service is only provided by two consultants and hence is very vulnerable should one be off for any reason or choose to leave. If the service was drop to only one AML/HR MDS and ALL specialist, the immediate plan is to send all AML/HR MDS and ALL patients to the Christie Hospital with de-skilling and very real financial risks. The AML/HR MDS and ALL consultants at BCUHB say they would be happy to support an all-Wales AML MDT but only providing the immunophenotyping and genetic services supporting the AML MDT achieve turnaround times in keeping with national standards as provided by both Birmingham and Liverpool including a single integrated

morphology/phenotyping/genetic report and AML/HR MDS and ALL expertise provided by Cardiff to underpin the chosen clinical pathway. They feel that they will be able to manage the introduction of the new specific inhibitors in Glan Clwyd, Bangor and Wrexham with the support of at least an all-Wales MDT and possibly a future AML clinical Network.

3) Cardiff and Vale University Health Board

i) Clinical service

Meeting held 12th August 2022 and written comments also received. Attendees Dr Raz Alikhan, Dr Jonathan Kell, professor Steve Knapper, sister Sarah Doherty and sister Jo Bagshawe. Feedback/final thoughts meeting 25/11/22 – attendees Mr Gareth Jenkins, Dr Raza Alikhan, Dr Jonathan Kell, Dr Wendy Ingram, Dr Ceri Bygrave, Dr Keith Wilson, professor Steve Knapper and Dr Emily Hopkins.

The clinical AML/HR MDS and ALL service within CVUHB is provided by 2.0 WTE myeloid specialists (Drs Alvares (0.5WTE) and Kell (1.0 WTE) and professor Knapper (0.5 WTE) and two (1.0 WTE) ALL specialists providing cover along with a specialist AML/HR MDS and ALL and Clinical trial CNSs and pharmacy support although there is not a AML/HR MDS and ALL dedicated pharmacist. The patients are managed in the dedicated haematology in-patient, Day Unit and out-patients within UHW although all these facilities are to greater or lesser extent inadequate - too few beds/Day Unit chairs/lack of isolation facilities etc. CVUHB also accepts secondary and tertiary referrals from across south Wales (except SBUHB) for younger AML/HR MDS and ALL patients fit enough to receive in-patient induction chemotherapy. Given the catchment area of south Wales (except SBUHB) UHW manages 60-80 new AML and 5-10 ALL patients per annum. All the initial diagnostic and prognostic work-up e.g. bone marrow examination including immunophenotyping/genetic sampling are undertaken within CVUHB. All newly diagnosed AML/HR MDS and ALL patients are discussed at the UHW AML MDT but given the limitations of the immunophenotyping and genetic services, patients will often need to be treated before a full diagnostic work up has been completed, necessitating repeat discussions at MDT and a less than optimal patients service.

In-patients admissions at UHW need to wait until one of the 17 general haematology beds becomes available and because of the pressure on beds AML/HR MDS and ALL patients are usually discharged back home (if they live near to UHW) or back to their referring local hospital outside CVUHB as soon as induction chemotherapy has been completed – the national standard is patients should remain as in-patients until bone marrow recovery following AML/HR MDS and ALL induction chemotherapy (SBUHB and BCUHB are able to comply with this standard). The shortage of beds at UHW often leads to patients being discharged to their referring hospital at very short notice (typically to free up beds for patients requiring urgent admission from within CVUHB or elsewhere in south Wales). This is often leads to difficulties due to inadequate communication between centres or local Haematologists not being able to offer the support required due to various reasons including inadequate local staffing/skills and access to a local Day Unit to undertake what is required e.g. platelet infusion.

The modus operandi of the AML/HR MDS and ALL service to offer clinical trials to all eligible patients but patients from outside CVUHBs immediate area, may have difficulties attending for trial directed tests/follow up.

The AML/HR MDS and ALL service at CVUHB is funded via local generic SLAs between CVUHB and other local UHBs. However, the generic SLA funding model does not reflect the complexity and extent of support AML patients require especially in the in-patient and Day Unit setting. Thus the AML/HR MDS and ALL service at CVUHB has lacked strategic planning to cope with the increase in AML/HR MDS patients, increased complexity of diagnostic and prognostic procedures and therapies which has led to inadequate funding such that there are too few in-patient beds, the in-patient ward itself is not to modern standards (lack isolation facilities, physically distant from the Day Unit), inadequate Day Unit facilities (lack of isolation cubicles for potentially very infective and sick AML/HR MDS and ALL patients) and specialist consultant expansion.

The AML and ALL consultants are part of the general haematological oncology on call service at CVUHB and hence are not available to advise external consultants out of hours should they have any new AML patients or issues with existing ones – even those who may recently have been under CVUHB's care.

The CVUHB AML/HR MDSconsultants feel that the introduction of the new specific inhibitors should not cause any delivery problems for CVUHB based patients but may for patients managed at other centres as they (CVUHB) do not have the resources at present to manage AML/HR MDS patients receiving such therapies in other UHBs. They feel an all-Wales AML MDT is essential and an absolute minimum going forward. Ideally, they feel there should be a fully funded AML network to manage all AML patients – in-patients, attending Day Units or outpatients - whether being treated with standard chemotherapy or the new specific inhibitors although without increasing resources at CVUHB they are not in a position to offer leadership or functionally contribute to such a network.

ii) Immunophenotyping service at CVUHB

Meeting held 19th August 2022 and written comments/information received (Alun Roderick).

Attendee Dr Andy Goringe (Haematology Laboratory Director at CVUHB).

The Immunophenotyping service at CVUHB resides within the Haematology Laboratory Directorate at UHW and started in the early 1980's initially as a local service to diagnose acute leukaemia and lymphoproliferative disorders. The immunophenotyping service is provided by:

Band 8a Section Lead	x1 – to retire in next 12 months
Band 7 BMS	x2 – x1 to retire in next 12 months
Band 6 BMS	x1 (Currently vacant)
Band 5 BMS	x1

Band 4 Associated Practitioner x1

with results interpreted and reports issued by Dr Andy Goringe who has no consultant back up when away but is presently supported by the MRCPath holding Band 8a who is due to retire soon.

The service has only ever been funded via local SLAs between CVUHB and other UHBs sending samples to the UHW immunophenotyping laboratory. This funding model has led to several problems notably a lack of strategic planning for managing the new indications for immunophenotyping many of which have no or inadequate funding (BMT, CAR T, MRD for acute leukaemia and myeloma, diagnosis of Myeloma and Paroxysmal Nocturnal Haemoglobinuria, non-commercial clinical trials), the new complex analyses (with increasing antibodies and fluorescent markers) which modern flow cytometry machines can undertake, as well as the ever increasing number of specimens as the population continues to age and hence the number of haematological cancer cases increases. In short the UHW immunophenotyping service appears to have received inadequate funding over the last 20 years due to a lack of new funding being identified for all the new indications for immunophenotyping and the increasing workload. This has led to reduced staffing levels due to difficulties in attracting and retaining the highly skilled laboratory scientists required for such a high pressure service. This in turn has led to very long turnaround times for formal results (up to over 2 weeks even for acute leukaemia patients – a verbal preliminary report is usually issued after 2-3 days) and failure to attend and input even into the local UHW AML/HR MDS/ALL MDT which is against both national haematological and Nice standards. There is an imminent threat as one of the senior laboratory staff took early retirement at very short notice and two of the most senior scientists (band 7 and band 8a) are due to retire within the next 12 months. Options to sustain the service are presently being considered within CVUHB.

One other issue is that IT within and beyond. CVUHB does not support easy and seamless integration of information to the existing AML/HR MDS and ALL MDT, or even for listing cases for UHW and the AWMGS does not issue results via the all Wales LIMS system. This would therefore require attention (and ? additional resources) if a single comprehensive integrated report to act as a resource for the patient care pathway decision making process by an all-Wales AML/HR MDS and ALL MDT is to prove fit for purpose.

The UHW immunophenotyping laboratory presently undertakes 293 acute leukaemia screening samples and 351 MRD analyses per annum.

4) Cwm Taf University Health Board Meeting held 22nd August 2022. Attendees Dr Hanadi Ezminga and Mr Anthony Cadogan. Feedback/final thoughts meeting 25/11/22 – attendees Dr Hanadi Ezminga and Mr Anthony Cadogan.

The AML/HR MDS and ALL service along with all other haematology services at CTUHB is provided by 3.0 WTE general haematology consultants at the Royal Glamorgan Hospital (RGH) although at present there is a 1.0 WTE vacancy and 2.0 WTE haematology consultants

(between 3 consultants) at Prince Charles Hospital (PCH) at Merthyr. There is no haematology sub-specialism including AML/HR MDS and ALL within CTUHB including in part due to RGH and PCH having no specialist haematology beds and at RGH no access to a dedicated Day Unit with specialist haematology nurses. There are no dedicated AML/HR MDS and ALL sessions for any of the consultants to sub-specialise (become AML/HR MDSlead) and there is a single CNS who works across both RGH and PCH and covers all haematological malignancies.

Initial acute leukaemia diagnosis is suspected based on a morphological assessment of peripheral blood (and sometimes bone marrow) undertaken within CTUHB. AML/HR MDS and ALL patients fit enough to receive intensive induction therapy are transferred immediately to UHW (beds allowing) for further investigations and if appropriate AML/HR MDS and ALL induction therapy. The consultants do provide joint care (Day Unit and out-patient assessments) under guidance of the CVUHB consultants when patients are discharged from UHW. Patients who develop neutropenic sepsis following induction or subsequent intensive chemotherapy, if possible get re-admitted to UHW (beds allowing) or if not possible get admitted to the general medical beds at CTUHB under the care of general medical physicians – CTUHB haematologists input is provided as required. Patients who are not fit for intensive induction chemotherapy are discussed at the CVUHB AML/HR MDS and ALL MDT at which a care pathway/treatment plan is devised and delivered in the PCH Day Unit/out-patients including venetoclax based regimens but due to a lack of resources no patients are entered into clinical trials. Due to these lack of resources (consultant sessions/AML/HR MDS lead, suitable Day Unit and Out-patient facilities, lack of specialist haematology nursing, CNS, pharmacy and R&D support) and present lack of AML/HR MDS and ALL expertise within CTUHB, they feel they will be unable to safely offer the new specific kinase inhibitors either as in-patients or Day Unit/outpatients and will require CVUHB to continue to provide the bulk of the AML/HR MDS and ALL service unless the resources within CTUHB are substantially increased. If resources did allow, the intention would be to repatriate the haematology service at Prince of Wales hospital (Bridgend), which is presently provided by SBUHB back to CTUHB.

The consultants at CTUHB are very supportive of an all-Wales AML/HR MDS and ALL MDT to direct care but would need a major increase in resources within CTUHB alongside an AML clinical care network where virtually the whole of the expertise is available to deliver the new specific kinase inhibitors within CTUHB and allow patients to be treated locally and have access to clinical trials.

CTUHB does not undertake any immunophenotyping or genetic AML/HR MDS and ALL laboratory services but expressed concerns about the timeliness of both of the present services provided by UHW and the AWMSG.

5) Hywel Dda University Health Board

Meeting held 25th August 2022. Attendees Dr Rhian Fuge, Dr Harry Grubb and Dr Sumant Kundu. Feedback/final thoughts meeting 25/11/22 – attendees Dr Harry Grubb and Dr Peter Cumber.

The AML/HR MDS and ALL service is spread across all 4 HDUHB hospitals – Bronglais (Aberstwyth – long-term locum Dr Cumber), Glangwili (Carmarthen – Dr Fuge and Dr Nicholas), Prince Philip (Llanelli – Dr Fuge) and Withybush (Haverford west Drs Grubb and Kundu) hospitals with in-patient beds and Day unit facilities at Glangwili and Withybush only. There are plans for a new hospital to be built (at present a site at St Clears is being considered) when it is expected services will be centralised from across the HDUHB catchment area onto this single site but this will take at least 10 years. There are 3 consultant vacancies (1 at Bronglais and 2 at Glangwili) presently filled when possible by locums, but unfortunately despite 8 years of trying they have been unsuccessful in substantively appointing to these vacancies and it is highly possible this situation could continue for the medium and possibly long term. There are 4 CNSs supporting all types of haematological malignancies across the 4 sites. Given the very large and poorly connected transport links across the HDUHB geographical area, all consultants work as general haematologists with no sub-specialisation and no AML/HR MDS lead.

Initial acute leukaemia diagnosis is suspected based on a morphological assessment of peripheral blood (and sometimes bone marrow) undertaken by consultants within HDUHB. AML/HR MDS and ALL patients fit enough to receive intensive induction therapy are transferred immediately to UHW (beds allowing) for further investigations and if appropriate AML/HR MDS and ALL induction therapy. The consultants do provide joint care (Day Unit and out-patient assessments) under guidance of the CVUHB consultants when patients are discharged from UHW. Patients who are not fit for intensive induction chemotherapy are discussed at the CVUHB AML/HR MDS and ALL MDT at which a care pathway/treatment plan is devised and delivered in the Withybush and Glangwili Day Unit/out-patients including venetoclax based regimens but due to a lack of resources no patients are entered into clinical trials. There is concern about the imminent arrival of the new specific inhibitors due to a lack of AML/HR MDS expertise (consultant and nursing), lack of staff (medical. Nursing, pharmacy) and in places (Prince Philip, Bronglais) lack of suitable physical resources so although these new agents should be able to be delivered locally without extensive AML/HR MDS expert input and more functional capability this will prove very challenging.

The main threat to the present and future service is the retirement of 3 of the established consultants within possibly 2-3 years (Dr Cumber at Bronglais) and in 5 years Drs Grubb and Sumant (Haverford west). The inability to attract consultants to the existing vacancies means there is a real risk of HDUHB having only 2 substantive consultants in a few years' time. Because of this very real risk the haematology consultants are starting to consider re-configuring the clinical service with more non-consultant clinical staff – physicians assistants, nurses, pharmacist – but these will need expert AML/HR MDS support including training and ideally daily input. It is highly possible that there will be inadequate consultant

cover even to review blood films and diagnose acute leukaemia e.g. Bronglais, so digital morphology review by an external centre may be required in due course.

The consultants within HDUHB are very supportive of an all-Wales AML/HR MDS and ALL MDT and if properly configured and delivered an AML clinical network with an appointed AML lead within HDUHB working very closely with AML expert colleagues across Wales.

There have been very high level discussions between HDUHB and SBUHB about merging their laboratory services (biochemistry, haematology, histopathology etc) which may lead to clinical samples – blood and bone marrow - being sent to Swansea for assessment including morphology. At the present time there are no plans to merge clinical haematology services across the two health boards.

HDUHB does not undertake any immunophenotyping or genetic AML/HR MDS and ALL laboratory services and do have some concerns about the timeliness of both of the present services provided by UHW and the AWMSG.

6) Swansea Bay University Health Board

Meetings held 29th July 2022 - attendees Dr Ann Benton, Ms Ceri Gimblett and 5th September 2022 – attendee Dr Mohite. Feedback/final thoughts meeting 25/11/22 – attendee Dr Ann Benton.

The AML/HR MDS and ALL service (dedicated in-patient ward and Day Unit) at SBUHB is based at Singleton hospital with out-patient clinics there as well as at Morriston and Neath-Port Talbot Hospitals. SBUHB also provides the laboratory and clinical haematology services for Bridgend hospital with AML/HR MDS and ALL patients managed at Singleton hospital. There should be 6 substantive consultants providing a fully comprehensive haematological service in SBUHB but due to difficulties in attracting consultants since Dr Ismail retired in January 2018, there are only 3 substantive consultants (Drs Benton, Sati and Mohite) and typically 3 locums in post. Attempts are being made to attract haematologists from overseas to substantively fill the vacant posts and support Dr Mohite who leads the AML services. Dr Benton expressed the view that unless such a consultant can be appointed, the AML service is vulnerable with only a single handed consultant but of course CVUHB does not have the capacity to take on this work. It is felt that a joint consultant appointment between for example Cardiff and SBUHB to try and attract such a AML/HR MDS specialist is not the best way forward for SBUHB. There is excellent specialised nursing, CNS and Pharmacy support within SBUHB but middle-grade medical staff are at times in short supply despite two SPRs being in post from the south Wales Haematology trainee rotation. However, SBUHB is very active in clinical AML and ALL trials. Given the medical staffing issues and possibly some bed capacity issues at Singleton, SBUHB has not been able to offer managing the AML/HR MDS and ALL patients from HDUHB and hence they are still being sent through to CVUHB.

SBUHB does not undertake any AML/HR MDS and ALL related genetic analysis and samples are sent to the AWMSG but does have an in-house immunophenotyping service purely for Swansea patients. This service has recently bought a new flow-cytometer (same model as used in UHW) and appointed two staff to run the service. Although there has been no

historical links between the immunophenotyping services at SBUHB and CVUHB, one of the new appointees recently attended Cardiff to gain access to their SOP's. Historically SBUHB has not been able to offer deep MRD analysis for their AML/HR MDS and ALL patients but the hope is that they will be able to in the not too distant future. SBUHB typically diagnoses 20-25 new AML's per annum which with a maximum of 4 immunophenotyping analyses per AML patients would equate to ~100 samples/year i.e. 2 per week.

The SBUHB consultants are very supportive of an all-Wales AML MDT and would be interesting in exploring how a AML clinical network might function.

D) Potential models for future commissioning.

The present delivery of AML/HR MDS and ALL services is piece-meal, lacking strategic direction, investment, capacity, resources and in places expertise. Given the impending issue of an increasing lack of substantive consultant haematologists (on top of unfilled posts in west and north Wales and Swansea), increasing number of patients, increased complexity of the diagnostic, prognostic and therapeutic paradigm, increased drug costs (more patients and more expensive drugs), the present AML/HR MDS and ALL service funding model is simply inadequate and if not addressed will lead to a serious deterioration in clinical care and worse survival outcomes compared to other UK centres. Outside Wales, AML/HR MDS and ALL services are centrally commissioned through the regional cancer networks which often provide a single service across many sites such as Manchester with a catchment population of 2.1m and Birmingham with a catchment population of 1.3m. Wales with its different hospital set up and UHBs does however already commission some cross UHB cutting services such as the Renal Network which is hosted by 1 UHB but is responsible for providing services across the country. A similar centrally commissioned AML/HR MDS network should improve clinical outcomes by ensuring clinical care excellence often in the local hospital with regional expertise support, allow more efficient use of medical, nursing and pharmaceutical resources, ensure cost efficient use and savings especially of the new specific inhibitors and oversee the transformation of AML/HR MDS therapy services from an in-patient intensive chemotherapy service to more less intensive chemotherapy/specific inhibitor combination therapies. However, this will only be successful if all aspects below are addressed.

1) WHSSC could consider the central funding of a regional all-Wales AML/HR MDS and ALL Multi-Disciplinary Team Meeting.

Given the rarity of AML/HR MDS and ALL and the rapidly changing diagnostic, prognostic and therapeutic paradigm it has been exceedingly difficult for local health board haematologists and non-AML/HR MDS specialising haematologists even within the main treatment centres, to keep their knowledge up to date, maintain and even develop the necessary local services. This problem has been compounded by an increasing number of

patients and a lack of investment in Cardiff especially in the diagnostic immunophenotyping service and ward capacity which has led in recent times to more work having to be delivered by non-specialist haematologist in their local hospital. At present, haematologists from around the region access the Cardiff & Vale AML/HR MDS and ALL MDT meeting to discuss new AML/HR MDS cases on an ad hoc, non-funded basis but this has no immunophenotyping or genetic input. The current meeting structure does not have the capacity to discuss all patients (new and those who have already received therapy) in a satisfactory manner. Patients should have a second MDT discussion at time of remission to determine longer term plans which may include transplantation, and at any other point when there is a significant clinical event. Access could also be extended to include expert Microbiological advice when need.

Central WHSSC funding to set up an all-Wales AML/HR MDS and ALL MDT which would meet twice weekly to ensure newly diagnosed patients wherever they present, get access to the most up to date diagnostics/prognostics and expert opinions in a timely fashion to ensure patients get the correct therapy to maximise their survival chances and ensure maximum cost efficiency when making therapeutic choices especially in the safe and cost effective use of the new specific inhibitors. Both specialist nursing and pharmacy input would also be required. This MDT would require access to digital morphology to allow each UHB to show the morphology of their newly diagnosed patients and expert immunophenotyping and genetic input and attendance at the MDT to discuss results which have been delivered according to national standards. The MDT would be led by an AML/HR MDS and/or ALL expert (protected sessions paid to undertake the role of MDT chair), decide on the most appropriate patient care pathway based on the immunophenotyping and genetic results. The MDT would have representatives (ideally consultants) from all UHBs and ensure the smooth handover of patients between the treating centres and the local UHB, allowing better monitoring of patients' wellbeing and drug toxicities and act as an educational resource.

The MDT would need to be hosted by one of the UHBs who presently treat AML/HR MDS and ALL patients with curative intent and have administrative support. Additional funding will also be required to enable the chosen phenotyping service and AWMGS to turnaround the test results according to national/international guidelines. Funding will also be required for administrative support for the MDT and this same individual could also be tasked with the assisting the Chair and other members of the all-Wales AML/HR MDS and ALL MDT to produce a single comprehensive and integrated AML pathology report including the morphological, immunophenotyping and genetic data along with the planned care pathway.

The above proposal:

a) Ensures all AML/HR MDS patients get access to expert AML/HR MDS opinion to inform their individual care pathway.

b) Brings Welsh immunophenotyping and genetic services into compliance with national and international standards which is not the case at present.

c) Ensure patients receive the correct therapy in the timeliest and most cost efficient manner.

d) Improves the efficiency of the existing AML /HR MDS and ALL MDT by having all necessary results available for discussion in a single MDT meeting.

e) Allow patients from ABUHB to be treated locally and relieve CVUHB of having to manage these patients.

f) By the AML/HR MDS and ALL MDT allowing all ABUHB AML/HR MDS patients to be treated locally, this reduces the pressure on CVUHB resources (in-patient beds, Day Unit etc) which could possibly enable CVUHB to undertake more BMT and CAR T services, and even offer some support should the AML/HR MDS and ALL service in SBUHB become unviable for any reason e.g single handed consultant not at work for whatever reason.

g) Brings north Wales into a Welsh AML/HR MDS and ALL MDT improving communications between Welsh centres.

The above proposal does not:

a) Address the issues of functionally delivering (and possibly with worse to come as consultants retire) the existing and soon to be introduced new agents in CTUHB and HDUHB due to insufficient specialist nursing, pharmacy support and in places physical facilities. Thus patients who could be treated nearer to home may still have to travel to Cardiff to safely receive the correct treatment.

b) Address the SBUHB consultant staffing issues.

2) In addition to 1) above, WHSSC could consider centrally commissioning of CVUHB to manage the care of AML patients in CTUHB and HDUHB.

Assuming SBUHB can continue to manage its own AML/HR MDS and ALL patients and that supported by the all-Wales AML/HR MDS and ALL MDT, patients (both intensive chemotherapy and new agents) from ABUHB can be managed locally using monies released by not sending patients to Cardiff (via the SLAs), then CVUHB could be centrally commissioned by WHSSC to provide AML/HR MDS and ALL care for patients from CTUHB and HDUHB. In effect this is simple transfer of funding from a SLA based model to central WHSSC commissioning. However, to iron out the many issues that arise within CTUHB and HDUHB as a result of the lack of resources at CVUHB leading to short notice discharges, poor communications at time etc there should be protected sessions as part of this commissioning for both CVUHB, HDUHB and CTUHB consultants to manage this AML/HR MDS and ALL services.

The above proposal in addition to the benefits from 1) above:

a) Allows CVUHB to strategically plan their AML/HR MDS and ALL care pathway better as future funding streams are more secure

b) Allow increased access for patients at CTUHB and HDUHB access to AML/HR MDS expertise.

c) With CVUHB effectively being made more responsible for the AML/HR MDS and ALL service within CTUHB and HDUHB, there would hopefully be better cooperation, training and knowledge exchange between all levels of staff e.g. nursing, pharmacy etc.

d) Lead to less disruption to general on call haematology arrangements within individual UHBs – see 3 below.

What this proposal does not do:

a) Address the issues of functionally delivering (and possibly with worse to come as consultants retire) the existing and soon to be introduced new agents in CTUHB and HDUHB. Thus patients who could be treated nearer to home may still need to travel to Cardiff to safely receive the correct treatment.

b) Address the SBUHB consultant staffing issues.

3) In addition to 1) above, WHSSC could consider centrally commissioning all the AML/HR MDS and ALL services within Wales which would be managed through a funded AML/HR MDS/ALL Clinical Network and hosted within one of the UHBs.

This is in effect is an extended version of the already WHSSC commissioned BMT and Haemophilia services whereby all resources required to deliver a safe and fit for purpose service are “owned and managed” by the AML/HR MDS and ALL network which has a management team with representation from all UHBs and specialisms (Nursing, Pharmacy, Immunophenotyping. Genetics etc). In this model, whole posts or protected sessions (Medical, Nursing, Pharmacy etc) will be required within all UHBs under the responsibility of the AML/HR MDS and ALL management board. The Network would be responsible for the day to day care of all AML/HR MDS and ALL patients in Wales including ensuring the patients are treated as near to home as possible, in the most appropriate (safety and expertise) facility and with the correct drugs. The strategic and functional delivery of all diagnostic facilities pertinent to AML/HR MDS and ALL, the developing and delivery of the individual patient care pathway and the correct treatments would be the responsibility of the AML/HR MDS and ALL Network management team including education, training, compliance with national standards, clinical outcomes and out of hours cover. The members of the AML/HR MDS and ALL Network would be expected to provide 24/7 out-of-hours telephone advice to ensure any health care professional, working anywhere in Wales and having issues managing an AML/HR MDS and ALL patient would have immediate access to the necessary expertise/advice. This model could incorporate the appointment of joint posts

across UHBs, the development of out-reach clinics with experts seeing patients in Day Units/out-patients nearer to home.

The above proposal in addition to the benefits from 1) above:

a) Ensure Wales has a fit for purpose strategy for AML/HR MDS and ALL care and the means to operationally deliver that strategy.

b) Would ensure the safe and best functional delivery of AML/HR MDS and ALL care to patients in CTUHB and HDUHB ideally near to their homes even if consultants numbers reduce further due to retirements.

c) Future proof SBUHB in case their haematology consultant vacancies are not filled.

d) Ensure general haematologists in HDUHB and CTUHB are kept up to date with AML/HR MDS and ALL developments and their own patients through the local consultant with protected AML sessions paid for by the AML/HR MDS and ALL Network.

e) **May** help attract and retain doctors west of Bridgend, as they will be more intimately involved in the care of some of the most clinically demanding (skills wise) but rewarding haematology patients.

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2. https://www.cancerresearchuk.org/about-cancer/acute-myeloid-leukaemia-aml/survival

3. The 5th edition of the World Health Organization Classification of Haematolymphoid Tumours: Myeloid and Histiocytic/Dendritic Neoplasms. Leukemia (2022) 36:1703–1719.

4. A British Society for Haematology Good Practice Paper: Recommendations for Laboratory Testing of Patients with Acute Myeloid Leukaemia in the UK. Awaiting publication.

Report Title	**Review of Specialised Commissioning in Haematology: Allogeneic Haematopoietic Stem Cell Transplantation, Salvage therapy in Non-Hodgkin's Lymphoma and Secondary Immunodeficiency**	**Agenda Item**	3.4
Meeting Title	**Joint Committee**	**Meeting Date**	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 Allogenic Haematopoietic Stem Cell Transplantation (AHSCT), salvage therapy for high grade Non-Hodgkin's Lymphoma (HG NHL) and Secondary Immunodeficiency in haematology patients.				
Specific Action Required	RATIFY ☐	APPROVE ☒	SUPPORT ☐	ASSURE ☐	INFORM ☒

Recommendation(s):

Members are asked to:

- **Note** the findings of the specialised haematology review in relation to the management of AHSCT, salvage therapy for HG NHL and treatment for secondary immunodeficiency in haematology patients,
- **Note** the options proposed for how specialised commissioning under WHSSC may address the opportunities, risks and challenges in these service; and
- **Approve** the following specific recommendations:
  - Management of AHSCT:
    - Commissioning responsibility for long term follow up (post 100 days) by the specialist AHSCT team is transferred from health boards to WHSSC,
  - Salvage therapy for HG NHL:
    - Current commissioning arrangements are retained,
    - The role of central commissioning is re-evaluated once an agreed national pathway for HG NHL is in place,
  - Secondary immunodeficiency:
    - Current commissioning arrangements are retained; and
    - Consideration is given to undertaking work at an all Wales level to evaluate the feasibility of a national sub-cutaneous immunoglobulin therapy service for patients with secondary immunodeficiency.

REVIEW OF SPECIALISED COMISSIONING IN HAEMATOLOGY: ALLOGENEIC HAEMATOPOIETIC STEM CELL TRANSPLANTATION, SALVAGE THERAPY IN NON-HODGKIN'S LYMPHOMA AND SECONDARY IMMUNODEFICIENCY

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 Allogenic Haematopoietic Stem Cell Transplantation (AHSCT), salvage therapy for high grade Non-Hodgkin's Lymphoma (HG NHL) and Secondary Immunodeficiency in haematology patients.

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 paper is one of 3 separate reports on the findings and recommendations from the review.

The purpose of the current report is to outline the main findings and proposals for the following 3 areas of haematology that were addressed by the review:

- The management of patients after Allogeneic Haematopoietic Stem Cell Transplantation (also referred to as Blood and Marrow Transplant (BMT) for complications occurring beyond 100 days;
- The provision of salvage therapy for high grade Non-Hodgkin's Lymphoma
- The management of secondary immunodeficiency.

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-Hodgkin's 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 (CVUHB), 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 is contained in ***Appendix 1***. This cover report provides a summary of the findings and options for each of the 3 clinical areas that are described in more detail in the full report. Preferred options for future commissioning arrangements are proposed for each.

3.1 Management of AHSCT after the first 100 days

Under current commissioning arrangements for AHSCT, WHSSC is responsible for assessment, transplant and post-transplant care for the first 100 days only. From day 100 onwards, commissioning responsibility for the management of complications associated with AHSCT is held by health boards. This is a long standing arrangement that is also a feature of commissioning post AHSCT follow up care in NHS England (NHSE). However, for north Wales, since WHSSC holds the contract with the Christie Hospital, all funding for AHSCT care provided by the specialist centre (including long term management post 100 days) is held by WHSSC. The review considered whether the full AHSCT pathway (from assessment, transplantation through to long term follow up) for adult patients should be centrally commissioned by WHSSC.

3.1.1 Epidemiology

Allogeneic (donor) HSCT is a treatment option for patients with blood cancers. Approximately 60 patients per year in Wales are treated with AHSCT. AHSCT can be curative but long term potentially life threatening complications occur in up to 60-70% of patients. These include graft rejection/failure, graft versus host disease (GVHD) and opportunistic infection due to long term immunosuppression which can occur for up to two years post AHSCT or even longer if ongoing immunosuppression is required to suppress GVHD.

3.1.2 Pathways

Patients in south west, south east and parts of mid Wales, who require AHSCT are referred to the south Wales BMT programme, led by CVUHB, and are treated by the specialist team at University Hospital of Wales. Patients in north Wales are referred to the Christie Hospital in Manchester, and in mid Wales to Birmingham.

Data from UHW on re-admissions after AHSCT, demonstrates that many patients will require re-admission for treatment of complications arising after 100 days (in

fact, the majority of re-admissions occur after 100 days). There is year to year variation, but on average the number of re-admission bed days occurring after 100 days are equivalent to over 2 dedicated beds. Management of later complications is therefore a significant part of the overall specialist service and follow up care pathway.

3.1.3 Key Findings

- There is clinical consensus that patients with complications of AHSCT cannot be safely managed by general haematology and require the specialist team to manage their treatment,
- In north Wales, patients remain under the direct care of the Christie Hospital for long term post-transplant follow up and complications management,
- In south Wales, while most patients are able to access care from the specialist team, there are cases where patients have had to be managed locally or had admission delayed,
- There is a strongly held view within the CVUHB clinical team that resourcing for the management of complications has been, and remains, inadequate. This constraint is believed to arise at least in part from the current health board to health board commissioning arrangements for re-admission after 100 days which are funded via generic service level agreements that are not designed to adequately reflect the resources required to meet the complex needs of this patient group; and
- As a consequence, the haematology service at CVUHB has to balance the needs of patients with post-transplant complications of AHSCT with the needs of other haematology patients that also require admission which can impact negatively on the ability to admit patients in a timely way.

3.1.4 Haematology in-patient capacity at CVUHB

The issue of haematology in-patient capacity constraints at UHW raised here in the context of post AHSCT care was also an issue highlighted in the first report for this review – management of acute leukaemia. The acute leukaemia report noted that there are opportunities for reducing this pressure through 2 mechanisms: i) the adoption of new therapies that can be delivered on an out-patient basis, and ii) through the potential that an intensive therapy service for acute leukaemia is developed at Aneurin Bevan UHB. These developments would support CVUHB's ability to admit AHSCT patients as well as other patients (e.g. for CAR-T).

In addition, a capital business case is currently being developed by CVUHB that includes improved infrastructure for the BMT and CAR-T services. This aims to ensure standards for maintaining JACIE accreditation can be met and provides an opportunity for increased capacity to meet the need for BMT/CAR-T over the medium to long term.

3.1.5 Options

Two options were proposed:

- Option 1: maintain the current commissioning arrangements
  - WHSSC commissioning to day 100; and
  - Health board commissioning post day 100.

- Option 2: centralise commissioning for full pathway
  - WHSSC to commission the full pathway to include all care that needs to be provided by the specialist team (including from 100 days post-transplant).

There was clinical support for option 2 to centralise commissioning. This was felt to provide the following advantages:

- Commissioning arrangements should reflect the specialist nature of the care required by patients with complications of AHSCT,
- Consistency and equity across Wales through aligning funding and commissioning responsibility for the full BMT pathway under WHSSC as a single commissioner,
- Enhanced opportunity through a single commissioner with responsibility for the full BMT pathway to consider the resources required by the service as a whole to meet patient needs and service standards via the WHSSC Integrated Commissioning Plan process; and
- Enhanced opportunity through a single commissioner to develop the service model for the management of AHSCT complications (including, for example, developing out-reach clinics with benefits for patients, efficiency in resource utilisation and developing the skills of the wider clinical community outside the specialist centre).

3.1.6 Preferred Option

It is proposed that option 2 - commissioning responsibility for long term follow up (post 100 days) by the specialist AHSCT team is transferred from health boards to WHSSC - is adopted as the preferred option.

3.2 Salvage therapy for high grade Non-Hodgkin's Lymphoma

Under current commissioning arrangements for high grade NHL, WHSSC is responsible for commissioning specialised diagnostics (including the All Wales Lymphoma Panel (immunohistochemistry/genomics) and PET-CT), autologous stem cell transplantation and chimeric antigen receptor T-cell therapy (CAR-T). Health boards are responsible for commissioning chemotherapy for first line treatment and salvage therapy (administered when patients do not respond or relapse after first line treatment). The primary question for the review was to consider whether salvage therapy should be centrally commissioned by WHSSC. During the discussions with health board clinical teams, wider pathway issues

were raised by clinical stakeholders (including the role of a regional MDT and complex in-patient treatment regimens).

3.2.1 Epidemiology

In the 3 year period 2017-2019 there were 1830 incident cases of NHL in Wales or just over 600 cases per annum (Welsh Cancer Intelligence and Surveillance Unit). Since high grade NHL accounts for 30% of all NHL, there are approximately 180 new cases of high grade NHL each year in Wales.

The majority (circa 75%) of patients are suitable for the standard first line chemotherapy regimen (RCHOP) which will cure approximately 60%-70% of patients. The remaining 30%-40% of patients will either not respond or relapse, and as a consequence require salvage therapy to stabilise their condition while their suitability or BMT or CAR-T is determined. Consequently, there are approximately 50 to 70 patients per annum in Wales who require salvage therapy.

3.2.2 Pathway

The majority of patients with HG NHL can be treated as out-patients in haematology day units; those with rarer forms of HG NHL are treated with regimens that may require in-patient admission (such as treatment for patients with or at high risk of central nervous system lymphoma, Double/Triple hit lymphoma or patients with Burkitt lymphoma).

3.2.3 Key Findings

- All health boards[1] currently provide salvage therapy for their own patients where this can be delivered at their haematology day units. They are therefore able to manage treatment for the majority of their patients.
- Given this treatment is locally provided, there was no clinical support for the need for central commissioning of out-patient delivered salvage therapy,
- BCUHB, CVUHB, ABUHB, and SBUHB are able to provide in-patient salvage treatment,
- Patients in HDdUHB and CTMUHB who require in-patient salvage treatment or in-patient care for rarer forms of HG NHL are referred to University Hospital of Wales, CVUHB,
- Powys residents who are referred to haematology services in NHSE(for example, Shrewsbury and onto Birmingham for specialist services) who require salvage therapy for lymphoma are treated in NHSE.
- There was concern over the perceived long turnaround times for final diagnostic reports from the Lymphoma Panel with risk that some patients may not receive optimal therapy as a result. Non-optimal first line

[1] Patients from Powys will be treated in the health board or NHS England Trust to which they are referred for haematology care.

treatment which leads to non-response or relapse would be expected to increase the number of patients requiring BMT and CAR-T. This issue is being addressed through WHSSC's performance management and escalation arrangements; and

- Additional pathway and service capacity issues included:
  - The need for a commissioned regional lymphoma MDT was raised by several health boards (it is noted that the existing lymphoma MDT at CVUHB partly functions as a regional MDT); and
  - CVUHB clinical team raised capacity constraints in UHW as affecting the ability to admit patients requiring complex in-patient care (e.g. Burkitt lymphoma and high risk CNS lymphoma) particularly from HDUHB and CTMUHB.

3.2.4 Options

Three options were proposed:

- Option 1: maintain the current commissioning arrangements
  - Salvage therapy would remain commissioned by health boards.
  - WHSSC to work with the AWLP to improve turnaround time performance.
  - Work is undertaken to develop and agree the national optimal pathway for lymphoma (it is anticipated this would be taken forward by the haematology site group of the Wales Cancer Network). Once an agreed national pathway is in place, the role of specialised commissioning in supporting the delivery of the pathway could be re-evaluated.
- Option 2: WHSSC commission a regional/national lymphoma MDT
  - The current MDT at CVUHB is centrally commissioned as a regional or national MDT
- Option 3: WHSSC commissions a regional/national lymphoma MDT plus complex in-patient treatment regimens (which may include non-standard first line treatment, proven or high risk of CNS lymphoma, in-patient salvage, treatment for Burkitt lymphoma).

3.2.5 Preferred option

It is proposed that at the current time option 1 – no change in commissioning arrangements – is the preferred option. Options 2 or 3, which would extend WHSSC's role, should be considered in the context of an agreed national pathway for high grade NHL. The review discussions indicated there is not currently a clinical consensus over this pathway. This work is first required to inform future consideration of the role of central commissioning.

3.3 Secondary immunodeficiency

Under current commissioning arrangements WHSSC is responsible for primary immunodeficiency only; the treatment of secondary immunodeficiency is the commissioning responsibility of health boards. However, WHSSC has funded treatment for secondary immunodeficiency for a small number of haematology patients where intravenous access has become compromised. These patients

have been funded to receive home delivered sub-cutaneous immunoglobulin therapy (SCIG) managed by the WHSSC commissioned immunology service at CVUHB. The review addressed the question of whether the treatment of secondary immunodeficiency in haematology patients would benefit from central commissioning under WHSSC.

3.3.1 Epidemiology

Secondary immunodeficiency can arise as a result of the underlying disease or as a result of therapy for that disease. It is treated with intravenous immunoglobulin (IVIG) therapy delivered by each health board for its own patients in haematology day units[2]. The number of haematology patients estimated by clinical teams to be receiving IVIG treatment currently for secondary immunodeficiency is:

Health Board	Patients receiving IVIG therapy
Aneurin Bevan	25
Betsi Cadwaladr	30
Cardiff & Vale	50 to 60
Cwm Taf Morgannwg	10 to 20
Swansea Bay	25 to 50
Hywel Dda	Not known
Total (approx.)	200+

3.3.2 Pathway

Each health board manages the provision of IVIG for haematology patients locally within their day unit facilities. The frequency that patients attend for treatment is variable depending on their clinical circumstances (typically between every 2 and every 6 weeks).

Immunoglobulin is procured on an all Wales basis. Advice is provided to Welsh Government by the All Wales Immunoglobulin Strategy Group.

3.3.3 Key findings

- There appears to be significant variation across health boards in the prescribing of immunoglobulins for secondary immunodeficiency in haematology patients.
- There are two tiers of IG provision: home based, self-administered sub-cutaneous immunoglobulin therapy for patients with primary immunodeficiency, and hospital day-unit based intravenous immunoglobulin therapy for patients with secondary immunodeficiency. On the assumption that home based SCIG provides a better experience and would be preferred by most patients, then this variation is also inequitable.

[2] For Powys patients referred to haematology services in NHS England, IVIG therapy will be provided by their NHS England service.

- While moving to home based sub-cutaneous IG treatment would release capacity in haematology day units, the general view across haematology teams is that these benefits would be marginal.
- Secondary immunodeficiency is increasing in incidence across a number of other specialties due to the increasing use of immunosuppressive therapies, including in neurology, rheumatology, dermatology and renal services. Therefore, patients under the care of these specialities who have secondary immunodeficiency will also require immunoglobulin therapy.

3.3.4 Options

- Option 1: maintain the current commissioning arrangements:
  - Treatment for secondary immunodeficiency would remain health board commissioned,
  - Inequity resulting from the differing treatments offered for primary immunodeficiency (SCIG) and secondary immunodeficiency (IVIG) would continue,
- Option 2: Central commissioning for haematology patients with secondary immunodeficiency:
  - WHSSC would commission sub-cutaneous IG for all haematology patients with secondary immunodeficiency in Wales, delivered by the immunology service at CVUHB,
  - However, two tiers of provision (inequity) would continue since patients with secondary immunodeficiency under the care of other specialties would be offered IVIG only,
- Option 3: WHSSC to commission care for all secondary immunodeficiency patients requiring immunoglobulin therapy:
  - This would provide equitable access to SCIG for all patients in Wales with secondary immunodeficiency regardless of their underlying condition and the specialty managing their care.

3.3.5 Preferred option

It is proposed that at the current time, option 1 is the preferred option. Option 2, while it would provide an equitable service to patients under the care of haematology, would mean two tiers of service would remain since patients under the care of other medical specialties would have access to IVIG only. Option 3, central commissioning of home delivered SCIG for all patients in Wales with secondary immunodeficiency, would be a significant strategic development affecting a number of clinical specialties. Given these implications, further work would need to be undertaken to assess the feasibility, advantages and disadvantages, and resource requirements, for such a service. This may be an issue that could be explored by the All Wales Immunoglobulin Strategy Group in the context of supply and prioritisation of immunoglobulins in NHS Wales.

4.0 RECOMMENDATIONS

Members are asked to:

- **Note** the findings of the specialised haematology review in relation to the management of AHSCT, salvage therapy for HG NHL and treatment for secondary immunodeficiency in haematology patients,
- **Note** the options proposed for how specialised commissioning under WHSSC may address the opportunities, risks and challenges in these service,
- **Approve** the following specific recommendations:
  - Management of AHSCT:
    - Commissioning responsibility for long term follow up (post 100 days) by the specialist AHSCT team is transferred from health boards to WHSSC,
  - Salvage therapy for HG NHL:
    - Current commissioning arrangements are retained,
    - The role of central commissioning is re-evaluated once an agreed national pathway for HG NHL is in place,
  - Secondary immunodeficiency:
    - Current commissioning arrangements are retained; and
    - Consideration is given to undertaking work at an all Wales level to evaluate the feasibility of a national sub-cutaneous immunoglobulin therapy service for patients with secondary immunodeficiency.

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.
Organisational Implications	
Quality, Safety & Patient Experience	The paper describes risks and challenges in the current service for patients requiring care for AHSCT, high grade NHL and secondary immunodeficiency.
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 AHSCT, high grade NHL and secondary immunodeficiency.
Legal Implications	No legal implications have been identified.
Long Term Implications	The paper consider the potential future benefits of central commissioning in 3 areas of haematology.
Report History	6 February 2023 – CDGB 23 February 2023 – Management Group 2 May 223 - CDGB
Appendices	Appendix 1 - Specialised Haematology Review Full report

Review of Specialised Commissioning in Haematology and Immunology

Options Paper for possible central commissioning by WHSSC of funding of Allogeneic Haematopoietic Stem Cell Transplant services beyond 100 days post-transplant, salvage therapy for high grade non-Hodgkin Lymphoma and Secondary Immunodeficiency in haematological patients.

Introduction.

Many highly specialised haematological services are provided by a relatively few haematological centres through local generic service level agreements. However, these arrangements are not underpinned by a national or regional strategy or strategic investment, do not necessarily reflect the level of expertise required, the true costs of maintaining and delivering such a service and inefficiency due to opportunities for better resource utilisation (skills and monies) being missed leading to an inferior clinical service. WHSSC have commissioned a review of three clinical areas where central commissioning through WHSSC may be considered a better and more efficient way of providing these services.

The 3 areas to be reviewed are funding of:

1) Allogeneic Haematopoietic Stem Cells Transplant services beyond 100 days post-transplant

2) Salvage and other rarer therapies for high grade non-Hodgkin Lymphoma including Burkitt's lymphoma

3) Secondary Immunodeficiency in haematological patients.

1) Allogeneic Haematopoietic Stem Cells Transplant services beyond 100 days post-transplant

A) Introduction

Adult allogeneic haematopoietic stem cell transplantation (AHSCT) has been the cornerstone of cures in acute leukaemias and some types of non-Hodgkin lymphoma and a minority of patients with Hodgkin disease for nearly 40 years. AHSCT is presently undertaken in Cardiff (~50 patients /year) for all patients in south Wales whilst all north Wales patients are treated in England especially at the Christie hospital in Manchester. In south Wales, Cardiff is commissioned to provide all AHSCT services for up to 100 days post transplantation whilst in north Wales all patients continue to receive their care from England even beyond 100 days with WHSSC invoiced for all the English work. AHSCT although very expensive, can be curative but

long term potentially life threatening complications occur in up to 60-70% of patients including graft rejection/failure, graft versus host disease (GVHD - both acute and chronic) and opportunistic infection due to long term immunosuppression which can occur for up to two years post AHSCT or even longer if ongoing immunosuppression is required to suppress GVHD. Thus GVHD, post AHSCT severe immunosuppression and resulting opportunistic infections are very specialist areas often requiring expertise and specialist drug therapy e.g. antiviral therapies, which are not routinely available outside of Cardiff. Although Cardiff will always try and re-admit these patients even beyond 100 days post SCT, the lack of commissioning alongside the issues of specialist bed provision within Cardiff means many of these cases end up being treated in local hospitals with little/no expertise and experience in either the conditions or the drugs used to treat them. This leads to a poorer and less efficient service in south Wales compared to those treated in north Wales all of whom are managed in an English AHSCT centre.

To address how big an issue this is for haematological centres in Wales, meetings were held with each UHB to ascertain if they feel central commissioning of AHSCT services beyond 100 days post-transplant would be of benefit for themselves and/or their patients.

a) Aneurin Bevan University Health Board

Meeting held 26th July 2022 and written comments also received. Attendees: Dr Chris Jenkins, Dr Ali Mahdi, Dr Eamon Mahdi. Feedback/final thoughts meeting 25/11/22 – attendee Dr Victoria Williams.

ABUHB said that they rarely have issues with patients presenting with complication of AHSCT post 100 days post-transplant as given their proximity to Cardiff most patients call Cardiff if they are unwell (regardless of whether less or more than 100 days post-transplant) and get assessed in Cardiff and if necessary admitted there. On those rare occasions when for whatever reason, patients get admitted to ABUHB, they are usually swiftly transferred to Cardiff. The consultants at ABUHB however agree that given the specialist nature and treatment of late (>100 days post-transplant) complications, these patients should be managed in Cardiff by the specialist AHSCT team.

b) Betsi Cadwaladr University Health Board

Meeting held 9th August 2022 - attendee Dr Ernest Heartin. Feedback/final thoughts meeting 25/11/22 – attendee Dr Ernest Heartin.

As above all SCT services are provided by English centres who directly invoice WHSSC, so a change in commissioning beyond 100 days post AHSCT would have no impact at BCUHB.

c) Cardiff and Vale University Health Board

Meeting held 12th August 2022 and written comments also received. Attendees Dr Keith Wilson, Dr Raz Alikhan, sister Sarah Doherty and sister Jo Bagshawe. Feedback/final thoughts meeting 25/11/22 – attendees Mr Gareth Jenkins, Dr Raza Alikhan, Dr Jonathan Kell, Dr Wendy Ingram, Dr Ceri Bygrave, Dr Keith Wilson, professor Steve Knapper and Dr Emily Hopkins.

The Cardiff SCT team provide all AHSCT services for south Wales performing around 50 AHSCTs per annum. With the increase in indications for SCT and the recently established CAR-T service for Wales, beds for re-admission for any post SCT complications including post 100 days has become increasingly difficult due to a failure of physical facilities at CVUHB to keep pace with increased service demands across the

haematological malignancy spectrum. As such there are no protected beds for patients requiring re-admission for post AHSCT complications. However, the aim of the Cardiff SCT service is that all patients post AHSCT including those >100 days, should be offered re-admission to UHW as this is where the expertise and experience of managing such complications reside As such, all AHSCT patients upon initial discharge following their AHSCT are reviewed very regularly at UHW and are instructed that should they become unwell, should contact UHW 24/7 for advice and review if required. . Unfortunately, however, due to capacity issues at UHW and adequate funding to meet the full needs of patients, this is often not possible.

UHW, has ~50 re-admissions/annum totalling 7358 days over the last 6 years, on average 1226 days/annum for post AHSCT complications even for some patients transplanted as far back as 2016. Table 1.

	Financial Year**					
Parameter	2016/17	2017/18	2018/19	2019/20	2020/21	2021/22
ALL						
Total Re-admission Days*	**939**	**1267**	**1640**	**1365**	**1173**	**974**
▪ 2021 AHSCT (N=41)					20	612
▪ 2020 AHSCT (N=48)				---	500	278
▪ 2019 AHSCT (N=46)			26	653	548	73
▪ 2018 AHSCT (N=54)		---	1329	546	34	---
▪ 2017 AHSCT (N=56)	61	1026	261	69	48	08
▪ 2016 AHSCT (N=48)	878	241	24	97	23	03
Swansea Bay UHB + Bridgend County++ *(Based on where patient reside)*						
Total Re-admission Days*	**102**	**99**	**256**	**183**	**166**	**131**
▪ 2021 AHSCT (N=7)					---	61
▪ 2020 AHSCT (N=7)				---	114	62
▪ 2019 AHSCT (N=9)			---	96	50	---
▪ 2018 AHSCT (N=13)		---	256	78	---	---
▪ 2017 AHSCT (N=12)	07	99	---	09	02	08
▪ 2016 AHSCT (N=12)	95	---	---	---	---	---
% of Total Re-admission Days in Total cohort	**10.9**	**7.8**	**15.6**	**13.4**	**14.2**	**13.4**

Table 1. Calendar year re-admissions 2016 – 21.

Re-admissions for Swansea patients accounted for 7-15% of all re-admissions.

Of all the 7358 re-admission days, 5,084 days (average 847 days/annum) are for patients post 100 days AHSCT. Table 2.

	BMT Calendar Year					
Parameter	2016	2017	2018	2019	2020	2021
ALL						

No. of AHSCT transplants in Calendar Year	**48**	**56**	**54**	**46**	**48**	**41**
No. with *readmissions*	36 (**75.0**%)	42 (**75.0**%)	40 (**74.1**%)	34 (**73.9**%)	27 (**56.3**%)	27 (**65.9**%)
No. with no readmissions in UHW	9 (**18.8**%)	12 (**21.4**%)	11 (**20.4**%)	10 (**21.7**%)	17 (**35.4**%)	10 (**24.4**%)
No. *RIP during Primary BMT Admission*	3 (**6.3**%)	2 (**3.6**%)	3 (**5.6**%)	2 (**4.3**%)	4 (**8.3**%)	4 (**9.8**%)
Total Primary Bed Days	**1353**	**1669**	**1570**	**1348**	**1443**	**1347**
Total Re-admission Days* (*Not by Financial year*)	**1313**	**1473**	**1909**	**1300**	**778**	**632**
▪ Total Re-admission Days **up to D+100**	439 (**36.7**%)	532 (**36.1**%)	601 (**31.5**%)	285 (**21.9**%)	230 (**29.6**%)	234 (**37.0**%)
▪ Total Re-admission Days **post D+100**	874 (**66.6**%)	941 (**63.9**%)	1308 (**68.5**%)	1015 (**78.1**%)	548 (**70.4**%)	398 (**63.0**%)
Primary Bed Day/Re-admission day Ratio	**1 : 0.97**	**1 : 0.88**	**1 : 1.22**	**1 : 0.96**	**1 : 0.54**	**1 : 0.47**
Swansea Bay UHB + Bridgend County[++] *(Based on where patient reside)*						
No. of Allo transplants in Calendar Year	**12**	**12**	**13**	**9**	**7**	**10**
▪ % of Transplants in Total cohort	**25.0**	**21.4**	**24.1**	**19.6**	**14.6**	**24.4**
No. with *readmissions*	5 (**41.7**%)	7 (**58.3**%)	8 (**61.5**%)	7 (**77.8**%)	5 (**71.4**%)	7 (**70.0**%)
No. with no readmissions in UHW	6 (**50.0**%)	5 (**41.6**%)	4 (**30.8**%)	0 (**0**%)	2 (**28.6**%)	2 (**20.0**%)
No. *RIP during Primary BMT Admission*	1 (**8.3**%)	0 (**0**%)	1 (**7.7**%)	2 (**22.2**%)	0 (**0**%)	1 (**10.0**%)
Total Re-admission Days* (*Not by Financial year*)	**113**	**125**	**334**	**146**	**176**	**61**
▪ Total Re-admission Days **up to D+100**	40 (**35.4**%)	45 (**36.0**%)	142 (**42.5**%)	51 (**34.9**%)	101 (**57.4**%)	41 (**67.2**%)
▪ Total Re-admission Days **post D+100**	73 (**64.6**%)	80 (**64.0**%)	192 (**57.5**%)	95 (**65.1**%)	75 (**42.7**%)	20 (**32.8**%)
% of Total Re-admission Days in Total cohort	**8.6**	**8.5**	**17.5**	**11.2**	**22.6**	**9.7**

Table 2. Financial year re-admissions 2016/7-21/22.

Re-admissions post day 100 account for 66-78% of all readmissions/annum with readmissions from Swansea accounting for 8-22% of total readmissions/annum (total 535 days, on average 89 days/annum). So, on average CVUHB is using 847/365 - 2.3 beds/day - managing patients re-admitted beyond 100 days post SCT which is at present funded through generic SLAs with the various other UHBs.

d) Cwm Taf University Health Board

Meeting held 22nd August 2022 - attendees Dr Hanadi Ezminga and Mr Anthony Cadogan. Feedback/final thoughts meeting 25/11/22 – attendees Dr Hanadi Ezminga and Mr Anthony Cadogan.

CTUHB has no specialist haematology beds and all SCT services given the proximity, are provided by CVUHB. So, patients who become unwell post AHSCT are told by CTUHB and CVUHB that they need to contact UHW immediately, be assessed there and if needs be re-admitted to UHW. The consultants at CTUHB have no plans to change the present post AHSCT arrangements and agree that given the specialist nature and treatment of late (>100 days post-transplant) complications, these patients need to be managed in UHW by the specialist AHSCT team, although they would welcome the opportunity if CVUHB were able to offer out-reach clinics within CTUHB, to assist with such clinics. This would not only be more convenient for AHSCT patients but also assist with educational needs of CTUHB consultants and possibly help attract and retain consultants and/or nursing staff.

e) Hywel Dda University Health Board

Meeting held 25th August 2022 - attendees Dr Rhian Fuge, Dr Harry Grubb and Dr Sumant Kundu. Feedback/final thoughts meeting 25/11/22 – attendees Dr Harry Grubb and Dr Peter Cumber.

HDUHB undertake no SCT activity at all. Autologous SCT services are provided by SBUHB under the direction of CVUHB, with CVUHB providing all AHSCT for HDUHB patients. As with CTUHB, all AHSCT are advised should they become unwell to contact CVUHB directly but given the physical distance some patients do spontaneously attend HDUHB services either directly or as advised by the UHW AHSCT team. Patients who are so unwell who do need urgent admission to HDUHB are typically transferred ASAP to UHW for specialist management. However, there have been rare occasions where due to a lack of available in-patient beds at UHW, patients have had to be managed within HDUHB. This has caused problems due to a lack of local medical and nursing expertise within HDUHB in dealing with post 100 day complications e.g. GVHD, opportunistic infections, pharmacy not stocking the therapeutic agents needed to treat these complications and a lack of nursing experience in delivering such therapies. As with CTUHB, the HDUHB consultants feel that all AHSCT with complications should be treated at UHW, but would welcome CVUHB providing outreach clinics for the routine follow up of AHSCT patients for both patient convenience and educational/staff attraction/retention reasons.

f) Swansea Bay University Health Board

Meetings held 29th July 2022 - attendees Dr Ann Benton and Ms Ceri Gimblett. Feedback/final thoughts meeting 25/11/22 – attendee Dr Ann Benton.

SBUHB provides autologous SCT services for all SBUHB (including Bridgend) and HDUHB patients. However, AHSCT services are overwhelmingly provided from CVUHB. SBUHB with its dedicated day unit and in-patient beds do occasionally see and manage AHSCT patients (often after discussion with UHW AHSCT consultants) who develop complications both pre and post 100 days but as above, many patients are seen and managed in UHW.

B) Potential option models for future commissioning of Allogeneic Haematopoietic Stem Cells Transplant services beyond 100 days post-transplant.

i) Leave present commissioning arrangements as they are.

At present north of Wales is well catered for with all AHSCT patients being completely managed by English centres (predominantly Christie Hospital, Manchester) with WHSCC being directly invoiced with south Wales patients overwhelmingly managed by CVUHB through generic SLA invoicing to the various UHBs from which patients derive. The present model has several drawbacks:

a) This has led to a lack of expansion of beds at UHW to manage post 100 day AHSCT complications which occasionally leads to problems at the local UHB level where patients may have to be admitted. This means there is a two tier service in Wales with northern patients being managed in a specialist centre whilst those in the south may not be.

b) Given the lack and uncertainty of funding for post 100 day AHSCT complications, there has been no attempt by CVUHB to develop in-patient services (extra beds) or out-reach clinics in local UHBs for AHSCT patients with or without complications. This is not only inconvenient for patients who may well be in the early stages of recovery from their AHSCT, but uses ambulance services (typically as AHSCT patients are so immunosuppressed they have an ambulance to themselves) if family/friends can't bring them to Cardiff and a missed opportunity for local haematologists to maintain/develop their clinical skills in post SCT complications management and possibly attract and retain haematology consultants which is an issue especially west of Bridgend.

ii) WHSCC to provide central commissioning for post 100 day AHSCT services.

The provision by WHSSC of ongoing commissioning for post 100 day services for AHSCT patients would enable:

- Commissioning arrangements to reflect the specialist nature of the care required by patients with complications of AHSCT;
- Consistency and equity across Wales through aligning funding and commissioning responsibility for the full BMT pathway under WHSSC as a single commissioner;
- Enhanced opportunity through a single commissioner with responsibility for the full BMT pathway to consider the resources required by the service as a whole to meet patient need and service standards via the WHSSC Integrated Commissioning Plan process.
- Enhanced opportunity through a single commissioner to develop the service model for the management of AHSCT complications (including for example developing out-reach clinics with

benefits for patients, efficiency in resource utilisation and developing the skills of the wider clinical community outside the specialist centre).

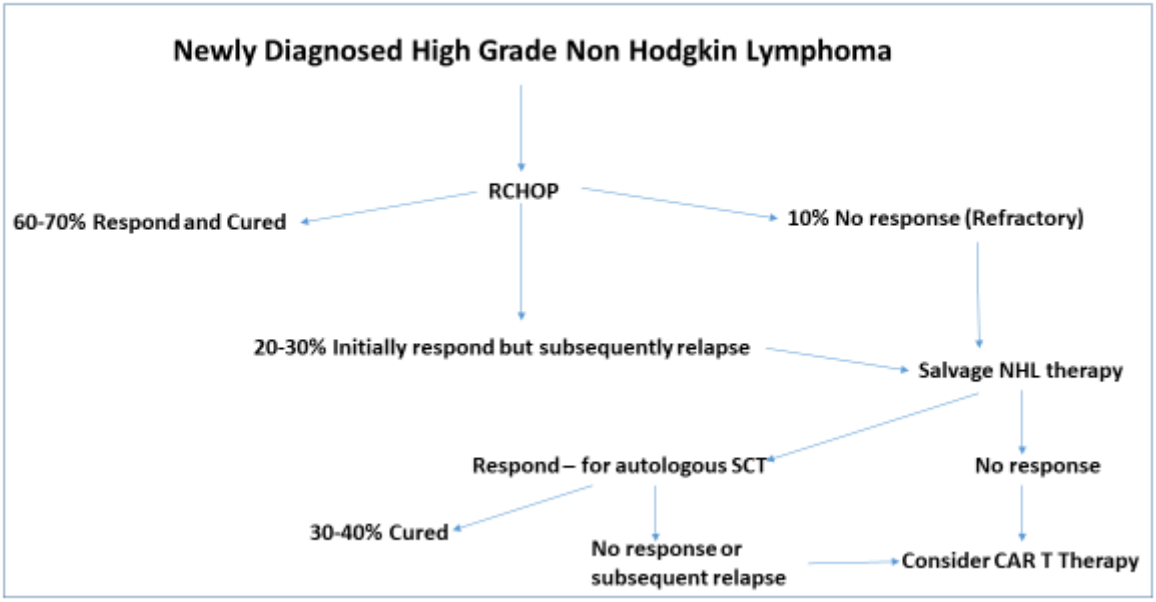
This option is supported by 3 of the 4 UHBs in south Wales (ABUHB, CTUHB, CVUHB, HDUHB) with Swansea happy with the present model although not opposed to a change in commissioning arrangements.

2) Salvage therapy for high-grade Non-Hodgkin Lymphoma (HG NHL).

A) Introduction

The improvement in survival of patients with high-grade NHL especially Diffuse Large Cell B-Cell Lymphoma (DLBCL) and Burkitts Lymphoma, has been one of the most successful in cancer history. With no cures for DLBCL prior to 1972 the introduction of the CHOP (Cyclophosphamide, Adriamycin, Vincristine, Prednisolone) chemotherapy regimen led to 40-50% cure. Autologous transplantation was added in 1997 for the 50-60% who relapsed post CHOP with rituximab being added upfront to CHOP (R-CHOP) in 2002 and Chimeric Antigen Receptor-T cell therapy (CAR-T) in 2017. This means that today between 80-90% of patients can be cured. Similarly, the introduction of the CodoxM/IVAC for Burkitts lymphoma has similarly improved outcomes. These results are underpinned by the introduction of PET scanning which is superior to CT scanning when determining complete from partial response.

So the present therapeutic pathway for no/low Central Nervous System risk, non-Double/Triple Hit DLBCL is:



However, there are other subtypes of HG NHL – high risk of CNS disease DLBCL, Double/Triple hit, Burkitts, Gray Zone – which require either additional therapy to RCHOP or a different therapeutic regimen. Salvage NHL therapy is a key component in bridging DLBCL patients who fail to respond to initial therapy or relapse

after achieving an initial response, determining who should be offered autologous SCT therapy and who should be considered for CAR-T therapy. There have been many different DLBCL HG NHL salvage regimens described but to date no comparative studies to suggest any given regimen is superior to any other. Salvage regimens used in the UK include:

- DHAP - Dexamethasone, Cytarabine and Cisplatin
- R- ESHAP - Rituximab, Etoposide, Cisplatin, Cytarabine and Methylprednisolone
- R-ICE - Rituximab, Ifosfamide, Carboplatin and Etoposide
- Mini BEAM – BCNU, Etoposide, Cytarabine and Melphalan
- R-IVE - Rituximab, Ifosfamide, Vinblastine and Etoposide
- RGDP - Rituximab, Gemcitabine, Dexamethasone and Cisplatinum

With the exception of RGDP all regimens require in-patient stay (3-8 days) whilst RGDP can be given in the Out-patient/Day Unit setting. Patients who relapse or fail to respond to their initial RCHOP therapy are often discussed at the unfunded monthly NHL MDT chaired by Dr Rowntree from CVUHB but typically attended by the SCT teams from both Swansea and Cardiff and the CAR-T team from CVUHB. There is little evidence that if a patient fails one particular salvage regimen that they are likely to respond to a differing regimen so typically patients receive only 1 salvage therapy especially now that CAR T therapy is available for those patients who fail their initial salvage therapy. At present there is no agreed salvage HG NHL regimen within Wales and in reality most centres have recently adopted the RGDP regimen which they deliver in their local UHB although for a very few patients a second salvage regimen has been recommended by the NHL MDT.

To gather further information as to whether WHSSC should consider commissioning of HG NHL salvage therapies, meetings were held with representatives from the various UHBs.

a) Aneurin Bevan University Health Board

Meeting held 26th July 2022 and written comments also received. Attendees: Dr Chris Jenkins, Dr Ali Mahdi, Dr Eamon Mahdi. Feedback/final thoughts meeting 25/11/22 – attendee Dr Victoria Williams.

ABUHB consultants say that they have moved over to using the RGDP salvage regimen within their own UHB. They do join the NHL MDT if they have a patient who may require the MDT input. If by chance they do give a differing salvage regimen they admit the patient to their own haematology ward. They cannot recall the last time they sent a patient to Cardiff (or anywhere else) for HG NHL salvage therapy. They do not support the need for central WHSSC commissioning of this service.

The consultants did however highlight that having a centrally commissioned service for the prophylactic treatment of patients with high risk of developing CNS lymphoma would be helpful. They also highlighted that it is taking up to 6 weeks (and rarely even longer) to receive the histological final report from the All Wales Lymphoma panel and this has meant that some patients have not necessarily received the optimal therapy that a more timely report would have enabled. Also, as with AML, the genetics for high grade

lymphoma is likely to impact choice of therapy in the very near future but at present the service is very slow- typically months to get reports. They would also support more resources being found to improve the lymphoma MDT.

b) Betsi Cadwaladr University Health Board

Meeting held 9th August 2022. Attendee Dr Ernest Heartin. Feedback/final thoughts meeting 25/11/22 – attendee Dr Ernest Heartin.

BCUHB have largely moved over to using the RGDP regimen which can be delivered at any of its 3 centres (Wrexham, Bangor and Rhyl). If an in-patient salvage regimen is deemed appropriate this is delivered at Glan Clywd in Rhyl. Heartin did not see the need and hence did not support central WHSSC commissioning of this service.

c) Cardiff and Vale University Health Board

Meetings held 12th August 2022 - attendees Dr Jonathan Kell, Professor Steve Knapper, Dr Raz Alikhan, sister Sarah Doherty and sister Jo Bagshawe and Dr Clare Rowntree (chair of CVUHB Lymphoma MDT to which many external UHBs bring their refractory/relapsed HG NHL patients) 17th November 2022. Feedback/final thoughts meeting 25/11/22 – attendees Mr Gareth Jenkins, Dr Raza Alikhan, Dr Jonathan Kell, Dr Wendy Ingram, Dr Ceri Bygrave, Dr Keith Wilson, professor Steve Knapper and Dr Emily Hopkins.

It was highlighted by Dr Kell and Prof Knapper that CVUHB still “appears” to undertake “a lot” of salvage HG NHL therapies for other UHBs which restricts access to beds for newly diagnosed acute leukaemia, elective SCT and urgent haematology patients on the UHW site.

They also highlighted that the monthly NHL MDT chaired by Dr Rowntree was “unfunded”. Dr Rowntree said that in any given week around 3 non CVUHB NHL patients are discussed at the Cardiff NHL MDT and this has highlighted several issues (not just around salvage therapy) including:

a) Less than optimal choice of therapy for initial treatment of DLBCL or other rare forms of HG NHL in some patients. This may in part be due to the delay in getting the definitive diagnostic histology report from the All Wales Lymphoma Panel.

b) Less than optimal delivery of initial treatment in patients who are refractory/relapse e.g delays in commencing therapies.

c) Lack of ability of external UHB consultants to attend the Lymphoma MDT which contributes to issues in a) and b) above.

d) The above 3 probably leads to less than optimal survival in south Wales and increased need for stem cell auto -transplant and CAR T therapy than should have been required. This leads to inefficient resource utilisation.

e) The funding for salvage NHL therapy is inadequate. For example, patients referred to CVUHB for salvage therapy are often sent to a local hotel to receive their therapy (as Day Unit patients in UHW) as there are no available in-patient beds in UHW.

f) There is no funding for a regional CNS prophylactic services or patients presenting with CNS lymphoma which typically requires hospital/hotel admission to Cardiff for high dose methotrexate therapy.

g) No funding/resources for CVUHB's Lymphoma MDT to function as a regional MDT. Given, the inability of external consultants to find time to attend Cardiff's Lymphoma MDT, a better option might be for Cardiff NHL consultants to attend the local UHB MDT but consultant sessions would be required for this.

h) No specific funding for patients referred to CVUHB with Burkitts Lymphoma- typically from HDUHB and CTUHB.

CVUHB would be supportive of WHSSC undertaking commissioning including supporting via additional funding the Lymphoma MDT, in-patient salvage, Burkitt's Lymphoma and regional CNS therapies. They also highlighted that it is taking up to 6 weeks to receive the histological final report from the All Wales Lymphoma Panel (AWLP) but thankfully the NHL MDT is attended by a histopathologist from the AWLP who often gives a verbal initial report.

d) Cwm Taf University Health Board

Meeting held 22nd August 2022 - attendees Dr Hanadi Ezminga and Mr Anthony Cadogan. Feedback/final thoughts meeting 25/11/22 – attendees Dr Hanadi Ezminga and Mr Anthony Cadogan.

CTUHB have no dedicated haematology in-patient beds but do offer R-GPD HG-NHL salvage therapy as an out-patient through their two day units at Royal Glamorgan and Prince Charles hospital in Merthyr. If a differing salvage regimen was to be given the patient would be referred to Cardiff for in-patient care, although the consultants at CTUHB could not remember the last time they sent such a patient to Cardiff. They would not be supportive of WHSSC undertaking commissioning for salvage HG NHL therapy as they don't see the need. They also highlighted that it is taking up to 6 weeks to receive the histological final report from the All Wales Lymphoma panel and this has led to delays in commencing treatment and that some patients have not necessarily received the optimal therapy. They would also support more resources being found to improve the lymphoma MDT.

e) Hywel Dda University Health Board

Meeting held 25th August 2022 - attendees Dr Rhian Fuge, Dr Harry Grubb and Dr Sumant Kundu. Feedback/final thoughts meeting 25/11/22 – attendees Dr Harry Grubb and Dr Peter Cumber.

As with CTUHB, HDUHB offer RGDP salvage therapy at both Haverford west and Carmarthen as out-patients through their day units, but if an alternative salvage regimen was indicated, the patient would be referred to Cardiff for treatment there. However, they can recall very few patients being referred to Cardiff within the last 12 months. They would not be supportive of WHSSC undertaking commissioning for salvage HG NHL therapy as they don't see the need. They did highlight that on occasions there is a delay in receiving a timely final histology report from the All Wales Lymphoma panel. They would also support more resources being found to improve the lymphoma MDT.

f) Swansea Bay University Health Board

Meetings held 29th July 2022 - attendees Dr Ann Benton and Ms Ceri Gimblett. Feedback/final thoughts meeting 25/11/22 – attendee Dr Ann Benton.

SBUHB typically offer RGDP through their day unit at Singleton hospital but if an alternative regimen was required they would admit and treat that patient themselves in Swansea. They would not be supportive of WHSSC undertaking commissioning for salvage HG NHL therapy.

B) Potential option models for future commissioning of salvage therapy for high-grade Non Hodgkin Lymphoma.

Several centres highlighted a less than optimal service from the All Wales Lymphoma Panel (AWLP) and delays – of possibly several months --- in receiving the final histology report. This has several important implications including patients potentially receiving the wrong or less than optimal therapy for their particular subtype of high grade NHL which has knock on effects of worse outcomes and increasing need for salvage therapies including the expensive auto stem cells transplantation (ASCT) and the very expensive CAR T therapy. As WHSSC funds the AWLP as well as salvage therapies (ASCT and CAR T), WHSSC could consider an audit of the present performance – in terms of timely histological reporting – and possibly performance manage any issues identified. This will hopefully improve clinical outcomes and ensure the most efficient use of the ASCT and CAR T resources.

i) Leave present commissioning arrangements as they are.

At present every UHB is offering local salvage HG NHL therapy in the form of RGPD with only a very few patients (probably ~ 10 year) requiring other regimens. Outside ABUHB, BCUHB and SBUHB these patients (from CTUHB and HDUHB) are sent to Cardiff. Given the small number of patients involved, the present arrangement of monies being recovered through generic SLAs may seem most appropriate.

ii) WHSSC provide funding for Cardiff Lymphoma MDT to act as regional/national MDT.

There does appear to be an issue of the lack of a proper regional NHL MDT which (along with the apparent need for an markedly improved turnaround times for histology reporting by the AWLP) would ensure that optimal therapy is initiated and delivered which would lead to better outcomes and more efficient use (possible cost savings) of resources presently used in WHSSC funded autotransplant and CAR T services.

iii) WHSCC to provide central commissioning for HG-NHL upfront non RCHOP therapy, “salvage” and CNS directed therapy.

CVUHB, SBUHB and ABUHB appear to be managing all the needs of their HG NHL patients although clarification of whether ABUHB is delivering differing upfront non RCHOP therapies e.g. Dose-adjusted R-EPOCH and CNS prophylaxis e.g. high dose methotrexate required. However, both CTUHB and HDUHB appear to be very dependent on the Cardiff Lymphoma MDT and any therapies except RCHOP and RGDP the costs of which CVUHB maintain are not covered by the present generic SLA arrangements.

3) Secondary Immunodeficiency (hypogammaglobulinaemia) in haematological patients.

Final draft HSCT, HG NHL, Secondary Immunodeficiency options proposal v 1.0 CF 211222

A) Introduction

Secondary immunodeficiency is not uncommon in many differing haematological disorders either as part of the underlying disease or as a result of therapy for that disease. These diseases include Chronic Lymphocytic Leukaemia (CLL) where up to 60% will develop hypogammaglobulinaemia, Multiple Myeloma and a minority of non-Hodgkin Lymphoma patients and treatments including rituximab, obinutuzumab, methotrexate, fludarabine, ibrutinib and CAR T all of which induce hypogammaglobulinaemia. Virtually all these patients are treated with intra-venous immunoglobulin (IVIG) therapy by their local haematologist in their local haematology Day Unit. This is in marked contrast to patients diagnosed with primary immunodeficiency who are managed by the WHSSC commissioned Regional Immunology Service based at UHW, Cardiff who have the means to train and monitor patients so that they can treat themselves at home using sub-cutaneous immunoglobulin (SCIG) as part of a home delivery programme in conjunction with the commercial company Calea. The indications for IVIG therapy and subsequent treatment regimens are provided in both Immunological and Haematological national guidelines.

Home delivered SCIG has many potential advantages over hospital administered IVIG including:

- Reduced risk of infection from venous catheters required to deliver IVIG
- No need for good venous access
- Free up beds/chairs in day units
- Reduced need for hospital transport
- Easier/less financial impact for patients – reduce “burden of treatment” which often compounds burden of disease
- Ease parking at hospitals as patients no not need to attend.

Immunoglobulin (both IVIG and SCIG) is presently contracted centrally by Welsh Government, who are advised by the All Wales Immunoglobulin Strategy group, so there are no potential impacts (savings or increased costs) by moving all patients to only using one IG product.

So at present there is a two tier system in Wales with haematology patients having to attend haematology day units and receive IVIG with the associated nursing and transport costs, and primary immunodeficiency patients SCIG treatment at home. However, the most rapidly expanding group of patients with secondary immunodeficiency are medical patients most notably from neurology, dermatology, renal and rheumatology due to the immunosuppressive therapies recently approved for very many medical indications. These patients are predominantly treated locally in a non-haematology Day Unit.

a) Aneurin Bevan University Health Board

Meeting held 26th July 2022 and subsequent written comments also received (Dr Chris Jenkins).
Attendees: Dr Chris Jenkins, Dr Ali Mahdi, Dr Eamon Mahdi. Feedback/final thoughts meeting 25/11/22 – attendee Dr Victoria Williams.

The ABUHB says it does offer IVIG on its various haematology day units for secondary immunodeficiency haematology patients. There are currently 15 patients in Royal Gwent and 10 in Neville Hall hospitals on IVIG.

The frequency of their IVIG varies between once every 2 weeks to once every 6 weeks. A few of the patients with CLL also only have their IVIG in the winter months. The nurses at ABUHB did feel that moving to home delivered SCIG would be beneficial by freeing up space in their "over-worked" day units. However, ABUHB consultants were less enthusiastic as the day unit visit sometimes doubles up as an opportunity for consultants to informally catch up with their patients.

b) Betsi Cadwaladr University Health Board

Meeting held 9th August 2022 - attendee Dr Ernest Heartin who also provided subsequent written information. Feedback/final thoughts meeting 25/11/22 – attendee Dr Ernest Heartin.

Primary Immunodeficiency patients from north Wales are treated in Liverpool and Manchester whilst the ~30 haematology secondary immunodeficiency patients receive IVIG in the 3 haematology day units and even community hospitals. BCUHB do not appear to be following national guidelines for treatment of secondary immunodeficiency and have a Pharmacy led in-house guideline which apparently means no new secondary immunodeficiency patients have been started on IVIG in the last 2 years[1]. Although home treatment would slightly relieve the pressure on the hospital day units this would be of marginal, if any benefit, although home treatment would probably be welcome by patients (and possibly ambulance services), some of whom have quite long travel times to and from hospital.

c) Cardiff and Vale University Health Board

Meetings held 12th August 2022 - attendees Dr Jonathan Kell, Professor Steve Knapper, Dr Raz Alikhan, sister Sarah Doherty and sister Jo Bagshawe (all Department of Haematology), 6th September 2022 - attendees Dr Tariq El-Shanawany and sister Emily Carne (both Immunology). 21st November 2022 - attendees Professor Stephen Jolles, Dr Tariq El-Shanawany and sister Emily Carne. Feedback/final thoughts meeting 25/11/22 – attendees Mr Gareth Jenkins, Dr Raza Alikhan, Dr Jonathan Kell, Dr Wendy Ingram, Dr Ceri Bygrave, Dr Keith Wilson, professor Steve Knapper and Dr Emily Hopkins.

CVUHB presently have 50-60 secondary immunodeficiency haematology patients receiving IVIG at its two haematology day units, whilst CVUHBs and other UHBs primary immunodeficiency patients (~300 for Wales) are managed by the regional Immunology Department with 80% receiving SCIG at home with the other 20% choosing to attend hospital and receive IVIG in the Immunology day unit. The Immunology Department have a team of band 5 and band 8 nurses (total 8 WTE but they do provide other services/roles within Immunology) who train, monitor, review on a 6 monthly basis and 12 monthly

[1] To note: Further information has been received from BCUHB to confirm they have adopted the NHSE IVIG guidelines 2021. Patients with secondary immunodeficiency commenced on IVIG: 4 in 2021, 5 in 2022.

undertake a home visit for patients receiving SCIG at home. SCIG is provided at home to patients by a commercial company (Calea) who invoice WHSCC for £2,000 per patient/year.

Haematology consultants and nurses at CVUHB feels that moving to home delivered SCIG would free up day unit chairs/beds and allow nurses to focus on the safe delivery of chemotherapy etc.

The regional CVUHB based Immunology Department would like to provide a single tier service for the whole of Wales but would need a marked increase in their nursing/administrative staff to manage this increased workload. Furthermore, given that secondary immunodeficiency is not purely a haematological problem but occurs in renal, dermatological, neurological and rheumatological conditions often due to the immunosuppressive therapies (rituximab, obinutuzumab, ibrutinib etc) used in these conditions, the Regional Immunology team feels there is differing access to immunoglobulin therapy being offered to these patients and several differing tiers of care and what is really needed is an all Wales solution for all the secondary immunodeficiency patients requiring expert medical and nursing input. They would be very happy to assist WHSSC, WG or any other party with advising as to how an all Wales secondary immunodeficiency service could be developed which would ensure equal access to expertise, better strategic planning for this rapidly increasing number of patients and more efficient use of what are limited but very expensive resources.

d) Cwm Taf University Health Board

Meeting held 22nd August 2022 - attendees Dr Hanadi Ezminga and Mr Anthony Cadogan. Feedback/final thoughts meeting 25/11/22 – attendees Dr Hanadi Ezminga and Mr Anthony Cadogan.

CTUHB presently delivers IVIG for its secondary immunodeficiency haematology patients through its two day units (Royal Glamorgan Hospital and Prince Charles Hospital, Merthyr). They feel that the provision of SCIG for its patients would free up beds/chairs on its day units but feel the impact would be marginal and they would like further information as to exactly how the service would look before being able to offer their support, or not. They do not know how many patients they have receiving IVIG at present but would estimate it is 10-20.

e) Hywel Dda University Health Board

Meeting held 25th August 2022 - attendees Dr Rhian Fuge, Dr Harry Grubb and Dr Sumant Kundu. Feedback/final thoughts meeting 25/11/22 – attendees Dr Harry Grubb and Dr Peter Cumber.

HDUHB presently delivers IVIG for its secondary immunodeficiency haematology patients through its three haematology day units (Haverford West, Carmarthen and Aberystwyth). They feel that the provision of SCIG for its patients would free up beds/chairs on its day units but feel the impact would be minimal and they have many other areas of higher priority they would like addressed. However, they do accept that given the geographical area covered by HDUHB that home treatment would probably be most welcome by patients and ambulance services. They do not know how many patients they have receiving IVIG at present.

f) Swansea Bay University Health Board

Meetings held 29th July 2022 - attendees Dr Ann Benton and Ms Ceri Gimblett. Feedback/final thoughts meeting 25/11/22 – attendee Dr Ann Benton.

SBUHB presently delivers IVIG for its secondary immunodeficiency haematology patients through its haematology day unit at Singleton hospital. They estimate they have 25-50 patients presently receiving IVIG at present. Although home delivery of SCIG would ease some of the burden on its day unit at present the day unit functions very well, the IVIG visits also double up at times for medical review and their day unit can manage the present workload. They also get specialist Immunology support from Dr Tariq El-Shanawany who visits from Cardiff, provides consultant cover for the Swansea Immunology laboratory and a monthly clinic.

B) Potential option models for future commissioning of secondary immunodeficiency management..

i) Leave present commissioning arrangements as they are.

At present every UHB is providing a service for their own haematological patients who develop secondary immunodeficiency through using IVIG in their day units, whilst WHSSC is presently funding a home service with primary immunodeficiency, with many potential benefits, in effect this means there is a two tier service within Wales. However, although most haematology departments agree that the development of a home delivery SCIG service would take the pressure off their haematology day units, the benefits will be marginal.

ii) WHSCC to provide central commissioning for haematology patients who develop secondary immunodeficiency.

If one accepts that there is a two tier system within Wales for providing immunoglobulin therapy and if one wishes to provide all such patients with the same level of service/access/benefit as that presently enjoyed only by primary immunodeficiency patients, then the WHSSC funded regional Immunology service based in Cardiff is the logical route. Using the 50-60 patients presently treated with IVIG at CVUHB as a baseline figure for a population of ~500,000, then extrapolating that figure across Wales' population of 3.3 million people, means regional Immunology taking on the care of an additional 165-198 patients to be added to the 300 primary immunodeficiency patients they already manage. So, although there are patient, hospital and ambulance benefits by moving to home delivered SCIG, this comes at a price as not only would a sizeable increase in resources be required by regional Immunology (increased nursing, administrative and possibly medical staff) to deliver this service, but £2,000 per patient will be required for home delivery of SCIG by Calea. So, given the existing resources presently required by regional Immunology to provide services to 300 primary immunodeficiency patients, an additional 200 secondary immunodeficiency patients being moved over to their care and receiving home SCIG, the additional resources could be around £6-700,00/annum (£400,000 for Calea and £2-300,000 for additional regional Immunology staff). Also, the present funding being used to purchase IVIG by the various UHBs will need to be transferred from UHBs to WHSSC/regional Immunology.

iii) WHSSC to commission care for all the secondary immunodeficiency patients requiring immunoglobulin therapy.

The fastest growing group of patients requiring IG therapy are medical patients – Dermatology, Rheumatology, Neurology and Renal. Providing central commissioning for haematology patients to receive home SCIG would therefore still leave a two tier system with medical patients not being included. For WHSSC to take on commissioning for all secondary immunodeficiency patients would be a major undertaking initially requiring an extensive review of the present service provision and the setting up of an all Wales service for secondary immunodeficiency patients. This would require extensive resources to be identified to provide such a service. However, such a service would provide patients with a higher level of care and equal access to immunoglobulin therapy which is presently not the case.