

**NID YW'R PAPUR YMA AR GAEL TRWY GYFRWNG Y GYMRAEG**

**Date:** Wednesday 23 October 2002  
**Venue:** Committee Rooms 3 & 4, National Assembly for Wales  
**Title:** Specialised Health Services for the Children of Wales

**Purpose**

1. The purpose of this paper is to:

- Report the outcome of Dyfed Powys Health Authority's public consultation on proposals to develop specialised healthcare services for the children of Wales, and
- Set out the action now being taken forward.

**Summary of Paper**

2. This paper describes the background to and the underlying issues highlighted by the review of specialised services for the children of Wales undertaken by the Specialised Health Services Commission for Wales (SHSCW) on behalf of the 5 Health Authorities, reports the outcome of public consultation and sets out the action now being taken.

**Timing**

3. This paper is being presented to the Committee at this time as this is my earliest opportunity to fulfil my undertaking to report to you the outcome of the public consultation which ended on 30 September and was considered by Dyfed Powys Health Authority Board on 14 October.

**Background**

4. The children of North Wales receive specialised services mainly in Liverpool. The children of South Wales largely receive specialised care in Cardiff, Bristol and Swansea and children in Powys often receive specialised care in Birmingham. A significant number of children from Wales rely on specialised care provided in England, including very specialised services at Great Ormond Street Hospital for Sick Children and Birmingham Children's Hospital.

5. In the light of increasing difficulties which have been experienced in maintaining and sustaining services that meet the ever increasing and demanding standards of care, the five Health Authorities asked SHSCW to carry out a comprehensive review of these services and prepare a strategy for their future development. This review was very timely in view of the lessons to be learned following the inquiries into the unexpected deaths of children receiving cardiac surgery in Bristol, some of whom were from South Wales, and what had happened at post mortem at Alder Hay and in the Gwynfa Unit in North Wales. The three inquiry reports, the Kennedy report, the Redfern report and the Carlile report respectively, all express, quite rightly, public expectation of services of excellence. Many of the recommendations following inquiries into these events lead to the need for change. All explicitly require that services are provided by appropriately trained staff including the non-clinical staff involved with the care of children. They also require that children are treated in a child-centred and safe environment and that services are the subject of open audit.

6. As part of the overall agenda of work to improve health services for children, the Welsh Assembly Government has recently begun work on a National Service Framework (NSF) for children's services. This NSF will form part of a framework within which health, social care, education and voluntary professionals, children and their parents can work together in the communities of Wales to improve the health and social care and their interface with education for the children of Wales.

7. On a wider front the Cabinet Sub-Committee on Children and Young People has formally adopted seven core aims for children and young people, one of which is that they "*enjoy the best possible physical and mental, social and emotional health, including freedom from abuse, victimisation and exploitation*" and both the NSF and this SHSCW Review will contribute towards this aim.

8. There are around 300 children in Wales that require specialised health care each year. The Welsh Assembly Government believes that the following principles must guide decisions on the planning, organisation and delivery of these services:-

- Children with specialised health care needs should receive the highest quality of care consistent with their needs.
- Every effort must be made to provide services within Wales wherever appropriate and possible.
- The nature of these conditions require clinical teams to manage a minimum number of patients to maintain skill levels and expertise.
- As much of the care as possible should be provided locally.
- Clear referral pathways and protocols should be in place to ensure that patients obtain the level of care they need and to avoid specialised services duplicating the work that should be carried out more appropriately at a primary or secondary care level.
- Since the events at Bristol, Alder Hay and North Wales, clear clinical governance requirements, including open clinical audit, demand that quality of care to patients must be a top priority and complicity with sub-optimal care is not acceptable.
- In order to provide sustainable services in Wales, we must reasonably expect to train our own core staff for the future. This will require a configuration of services to meet future training requirements.
- The nature of our professional and training links with England demands that we pay great attention to what is happening there. However, we can also look to other countries and communities to learn from their experience in providing specialist services.
- In reaching any conclusions about the provision of services, both the positive and negative implications of decisions for other services must be considered.

### **The SHSCW Review**

9. On 2 May, SHSCW published the outcome of its review in the document entitled '*The Review of Tertiary Services for Children*'. The issues needing to be addressed include:-

- Doctors and clinical staff caring for children with rare and complex conditions must use their skills regularly to deliver care to the highest standards. Increasingly doctors and other professionals are becoming subject to regular reviews of their performance and continuing professional development. This means doctors treating uncommon conditions and who must perform rare procedures, should not just carry them out on an occasional basis. This is particularly important where they are responsible for

training new staff.

- Doctors' results need to be compared to others carrying out similar work, as a safety check and to ensure that the best practice is shared.
- Specialised services must serve a large enough population to be clinically and economically viable. There must be enough children being treated to maintain the skills and experience of the clinicians and other health professionals involved in care.
- In-patient services must be provided on a 24-hour basis 7 days a week. If a service relies on just one consultant it can only be partially available because that person needs to sleep and to take time off for study and holidays. Thus consultants need to work in teams and there must be enough referrals for each to maintain their skills.
- Doctors and clinical staff must work reasonable hours and their employers must comply with the European Working Times Directive.
- Support services, equipment and facilities should be suitable for children and young people of different ages and their families.
- Like any other part of the health service, specialised health services need to comply with the law and government policy for children. So, for example, children should not be treated on adult wards unless there are exceptional circumstances.

### **The SHSCW Strategy and Public Consultation**

10. In response to the findings of the review, SHSCW also published a second document on 2 May, '*A Special Service, The Future of Specialised Healthcare for the Children of Wales*', which set out its proposed strategy for maintaining and developing services aimed at ensuring that children of Wales receive services matching the best in the UK. The strategy made a number of recommendations; these included a reconfiguration of some specialised services in South Wales, a strengthening of existing specialised services and continued partnership arrangements with specialist hospitals in England for Welsh children, where appropriate. The strategy also highlighted the need to develop standards for the services and to improve and strengthen local paediatric facilities. An integral part of the proposals to ensure quality and safety, which is a direct response to the Kennedy report on children's heart surgery at Bristol Royal Infirmary, is to extend the open clinical audit programme already in place for paediatric intensive care and paediatric cardiac surgery.

11. The five Welsh Health Authorities considered these two SHSCW reports carefully and subsequently agreed that Dyfed Powys Health Authority should lead a wide ranging public consultation on the recommendations made by SHSCW for major service changes. The consultation also sought public views on the principles of strengthening specialised children's services by developing clinical networks and standards of care which would be developed by specialty specific groups.

### **Chief Medical Officer's Group**

12. The consultation process has made it essential to be explicit about the definition of a clinical network, how networks function and the accountabilities and responsibilities of networks. As reported to Health and Social Services Committee on 17 July, I asked the Chief Medical Officer for Wales to advise me on the feasibility of establishing managed clinical networks for specialised children's healthcare services. The Chief Medical Officer established a local group comprising stakeholders, including parents, with an interest in these services and an independent expert advisory group of specialists from outside Wales. This work has brought clarity to the debate and has determined an accepted definition of managed clinical networks, the principles on which such networks will operate and the essential characteristics of their design and operation.

13. The outcome of the Chief Medical Officer's work has shown that:-

- Managed clinical networks are a way forward – they need to be flexible and individually designed according to particular service needs.
- The work that SHSCW has commissioned is important and urgent but this does not take sufficient account of the 'vertical' networking requirement for networks and needs to allow for primary care and secondary care network relationships.

- Other areas of children's health care also need strengthening – 'generalist care; community and primary care – if tertiary care is to work properly.
- There is sufficient work to be done around quality standards for a project in its own right across all paediatric specialties.
- Infrastructure especially IM&T is a prerequisite and every network will need a communications protocol.
- Protocols should also address 'access'.
- Serious work on public involvement is needed.
- This whole reform process amounts to major clinical redesign. It will need formal project management.
- Investment will be needed in organisational and personal development. Clinical leadership skills should be fostered.
- Network 'ownership' of fixed resources like beds/theatres/specialised kit needs to be explored and understood.
- There is a need to be realistic about the future and accept that this is a major change agenda.
- Clinicians, with management support, will have to lead network development themselves - based on common ownership of the corporate resources and a consensus management style. External mentors and quality assurance arrangements will be needed.

14. A copy of the Chief Medical Officer's full report is attached as Annex One.

## **OUTCOME OF CONSULTATION**

15. The Dyfed Powys Health Authority has informed me that the outcome of consultation was considered at its Board meeting on 14 October. A summary of what was noted and agreed is as follows:-

- The widespread support for strategy, principles, standards and proposals for providing specialised children's services of excellence for the children of Wales.
- The widespread support for the strategy for ensuring that each child with a complex or rare condition receives a standard of care that compares well with the best in the UK, is endorsed.
- The widespread support for a designation process for specialised children's services and that the Welsh Assembly Government should be asked to establish a Designation Board.

16. The consultation has also shown that there are concerns about travel costs and the need for accommodation for parents when children are admitted to hospital. Dyfed Powys Health Authority has asked the Welsh Assembly Government to explore ways of providing financial support to parents to help with travel costs and have agreed that SHSCW ensures that good quality parental accommodation is available from hospitals admitting children from Wales for specialised health care. This must apply to hospitals in Wales and in England.

17. The Health Authority has recommended the following in respect of the proposals for major service changes:

### **Paediatric cardiac services in South Wales**

- Paediatric cardiac services should continue to be provided as a partnership between Bristol Children's Hospital, the University Hospital of Wales and the District

### **Paediatric nephrology in South Wales**

- the paediatric nephrology specialty specific group should complete its work to develop standards, care pathways and protocols in collaboration with parents and other stakeholders
- The paediatric inpatient nephrology service, as a partnership between Bristol Children's Hospital, the University Hospital of Wales and the District General Hospitals and put in place on an urgent temporary basis, should be continued in the interim
- In an effort to resolve their concerns about the future of this service, further discussions should take place with Iechyd Morgannwg Health Authority and its two local Community Health Councils, who have objected to the proposed change. These discussions should take place in conjunction with Cardiff Community Health Councils and Bro Taf Health Authority and should be completed by the next Dyfed Powys Health Authority Board meeting on 3 December.

### **Paediatric neurosurgery in South Wales**

- Three of the four South Wales Health Authorities believed that the paediatric inpatient neurosurgery service should be based in an NHS Trust with the appropriate support facilities, which include paediatric intensive care, children's oncology and other specialised children's services. As well as inpatient care, paediatric neurosurgical services include follow up services, physiotherapy and other supporting services that can be provided locally. Emergency neurosurgical services for children could also be provided in association with adult services although subsequent referral to specialist paediatric inpatient facilities may be necessary. Iechyd Morgannwg Health Authority could neither support nor reject this proposal believing there to be insufficient evidence available to reach a properly informed view, however, two of their Community Health Council's object to this proposal.
- In view of concerns over insufficient information to form a view and objections from two Community Health Councils, SHSCW should further develop the option appraisal for the provision of neurosurgical services for children in South Wales. This process will identify the appropriate location of key elements of a paediatric neurosurgical service including inpatient care, follow up services, physiotherapy, and other supporting services that could be provided locally. This process will also look at whether emergency neurosurgical services for children can also be provided in association with adult services and the need for subsequent referral to specialist paediatric inpatient facilities may be necessary.
- The Welsh Assembly Government be asked to appoint an independent chair for the option appraisal process and the group established should include parents, voluntary organisations, health care professionals, community health councils, NHS Trusts, local health groups and health authorities.
- Iechyd Morgannwg Health Authority be asked to support the process by making available all the base data used by the Director of Public Health in his report and some time of a public health specialist.
- The work of the specialty specific group set up to develop standards of care for neurosciences be supported in such a way that it is able to complete the work on standards, care pathways and protocols quickly. This will enable the Chief Medical Officer's expert group to quality assure the work and then it can be used to inform the option appraisal process.
- In order to address concerns about care pathways and clinical outcomes for the existing service, a full 2-year independent retrospective audit of all children's neurosurgery operations should be carried out in Cardiff and Swansea. While this work is being undertaken the Cardiff and Vale and Swansea Trusts must ensure that children are provided a safe and appropriate service.

### **Action**

21. Now that the results of consultation have been reported to me, I require the following action to be taken :

- a. Dyfed Powys Health Authority must enter into and complete its post-consultation discussions with Iechyd Morgannwg and Bro Taf Health Authorities and local CHCs on the disputed proposals for major service changes and report progress to me as soon as possible following its next Board meeting on 3 December 2002.
- b. I accept the conclusion of the consultation and the Chief Medical Officer's work that a managed clinical network is the best way forward for the provision of paediatric neurosurgical services. I also accept the view reported to me that some emergency neurosurgical services for children can be provided in association with adult services and I require that this be considered as part of the option appraisal. SHSCW will further develop the option appraisal for neurosurgery services in South Wales. This work must be completed by Spring 2003. This process will inform the work on developing managed clinical networks to be carried out by the Chief Medical Officer. A priority for the Chief Medical Officer's work must be to draw up firm proposals for a managed clinical network for paediatric neurosurgery. This will ensure continuity of the development work during the forthcoming restructuring of the NHS in Wales in which health authorities will be abolished and the new Health Commission Wales (Special Services) will become responsible for commissioning specialised and tertiary services in Wales. I have asked the CMO to complete her aspects of this work by December 2003.
- c. An independent chair will be appointed immediately by the Welsh Assembly Government to oversee the option appraisal process for paediatric neurosurgical services.
- d. The question of reimbursing travel and accommodation expenses will be explored.
- e. I require that the consideration of the establishment of a Designation Board for children's specialised health services be completed by Spring 2003.
- f. I have asked the Chief Medical Officer to develop her general proposals for managed clinical networks for specialised children's health care services and to take forward the other related work she has identified in her report to me. This work will be put on a formal footing with the appointment of a project manager and the development of a funded project plan for implementation. It is anticipated that this work will take two years to complete.
- g. A new professorial chair in Pre-hospital Emergency Care within the University of Wales College of Medicine is proposed and I am pleased to endorse this development. It will serve as a foundation for looking at the evidence and will provide the best medical care in emergency situations such as head injuries and road traffic accidents.

(h) The development of managed clinical networks will be integral to a new national strategy for specialised and tertiary services, the preparation of which will be led by the Director of NHS Wales. This work will also take account of the recommendations for action at a national level set out in the report of the Independent Review of Tertiary Services at Swansea NHS Trust and will be completed by the Summer 2003.

- i. I have previously announced that we will be appointing a Director of Healthcare Services for Children and Young People. This appointment will be made by the end of December 2002. The postholder will act as the "champion" in laying the foundations for the development of a first class service for children's healthcare in Wales. This appointment will be critical to the development of the All Wales "Institute for Child Health" in laying the basis for a comprehensive research network across all DGH and primary care based children's health care services. The Director will work in support of the CMO in taking this forward.

## **Compliance**

22. Health service provision functions are covered by Sections 1-3 of the NHS Act 1977, transferred to the Assembly and delegated to me. There are no issues of regularity or propriety.

23. There are no financial implications as a direct result of this paper for the National Assembly. The work I have asked the Chief Medical Officer to develop on managed clinical networks will have some financial implications in terms of implementation which will need to be detailed in her further advice to me.

## **Action for the Committee**

The Health and Services Committee is invited to:

- note the outcome of public consultation on proposals to develop specialised health care services for the children of Wales, and
- note the action I have asked to be taken forward
- note that I will report progress on this work in my Monthly Reports.

**Jane Hutt**

**Minister for Health & Social Services**

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**Annex 1**

### **Managed Clinical Networks for Specialist Children's Services**

*"clinicians working across traditional boundaries in order to provide more effective care for patients"*

#### **Introduction**

This paper reports work, requested by the Minister for Health and Social Services and led by the CMO, to examine the feasibility of establishing managed clinical networks for specialist children's services.

It addresses the *needs of Welsh children and their families* and how they can best be met by drawing on appropriate services from providers, within Wales or elsewhere in the UK depending on the particular needs of individual patients and their families.

#### **Background**

This work is intended to inform the outcome of current consultation by the Specialised Health Service Commission for Wales (SHSCW) on the future of children's tertiary services in Wales "A Special Service" and assist the recently commenced work, in Wales, on a National Service Framework for children's healthcare services.

The overall policy context for shaping and delivering services was set out in the Plan for NHS Wales "Improving Health in Wales, which built on the earlier work on acute services in Wales, published as "Access and Excellence"; This has particular implications for the way in which services will be planned, organized and delivered in the future.

The recently published review of all tertiary services provided by the Swansea NHS Trust with its emphasis on need for wide ranging managerial and other reforms is also relevant to this work as are current national negotiations on consultant medical staff contracts.

#### **Approach**

To undertake this work, two groups were convened, the first to represent those clinicians and organizations offering specialist services for Welsh children including providers from Bristol and Liverpool. Welsh CHCs and parents were also represented on this group. The second to provide a reference panel of experts from other parts of the UK nominated by the Royal College of Paediatrics and Child Health (RCPCH) and the Royal College of Surgeons (RCS).

Each consultant paediatrician in Wales was invited to talk individually with the CMO about managed clinical networks in relation to specialist services. These ongoing discussions have generated additional perspectives that are incorporated into the report.

Work on networking models for paediatric subspecialties, previously initiated by SHSCW, has also been taken into account.

The multi professional nature of children's care and the implications for clinical networks are fully acknowledged but this initial work has focused on the views of paediatricians – wider involvement is a crucial next step.

*Appendix A lists members of each group.*

## **The Context**

In Wales, we have valuable experience in the recent development of managed clinical networks for services related to cancer and coronary heart disease. The appropriateness of managed network approaches to the planning, organization and delivery of children's services is very widely supported.

A number of successful examples of networking already exist, within children's services. This work builds on that already done in developing clinical networks, examples being those for paediatric intensive care, paediatric gastroenterology and child and adolescent mental health services.

These range from very informal service partnerships to more structured relationships, some emerging and some longstanding. The Child and Adolescent Mental Health Network is formally established on the basis of the principles of a managed clinical network, and the network for paediatric critical care is close to an MCN model.

The population of Wales is currently less than three million, with a falling birth rate. With such a population base it is clearly not appropriate to expect to sustain expertise in the full range of specialised services. Interaction with providers in other parts of the UK is essential and in many instances is already routine.

North Wales has traditionally looked to Liverpool for most of its specialised support. In the south, Bristol has supplemented the specialised capacity of Cardiff in some aspects of care and other centres in England have provided similar support. Wider European and global networks are also utilised.

Wales has, and would wish to develop, particular areas of specialised expertise to make an appropriate level of contribution to these wider networks. A good example is the collaborative working on paediatric intensive care with Bristol to provide a service for children from England when required.

## **Definition**

For the purpose of a common understanding, the Advisory Group adopted the Scottish definition of managed clinical networks:

"linked groups of health professionals from primary, secondary and tertiary care, working in a coordinated manner, unconstrained by existing professional and Trust/Health Authority boundaries, to ensure equitable provision of high quality and clinically effective services".

## **The Network Concept**

*Regardless of where they live in Wales all children, equally, must have access to appropriate, efficient and dependable services, which fulfil agreed standards, provided as*



*close to home as possible.*

## The Vision

The emphasis in clinical networking is on *connection and partnership* rather than isolation and self-sufficiency, on *distribution of resources* rather than centralisation, and on *maximising the benefits for all patients* rather than the fortunate few. Care is delivered seamlessly by a chain of interconnected people and the services they provide. The relationship between these people and their services forms the structure of the network and governs its operation. Professional relationships have to be clearly defined for staff to function effectively, realise full potential and feel valued.

## What They Are

Managed Clinical Networks (MCN) are a formal expression of the clinical relationships that normally exist in the care pathway of clinical conditions or patient care groups. They seek to span the organisational boundaries of trusts, individual hospitals, primary care groupings, and professional interests, voluntary care groupings and other networks. The aim must be to provide integrated care that is seamless from the perspective of parents and children.

As such MCNs are not an additional organisational layer but a means of co-ordinating health professionals and supporting services. They are designed to further the quality of service delivery with the minimum of organisational support. In terms of children's healthcare services, this will include emphasis on the participation of parents and children.

## Function

The principal function of networks is to ensure the quality, safety and efficiency of clinical services and to improve wherever possible patient experience and outcomes. This will be achieved by the adoption, development and review of agreed standards both clinical and managerial and through the implementation and monitoring of care pathways, which will be evidence based where possible.,

In this way, networks will have a prime role in the pursuit of continuous improvement, informing and driving the commissioning process, in advising on workforce issues and influencing the Research and Development agenda.

## **Principles**

The network will, on behalf of its constituent member organisations:

- Ensure a 'child and family centred' service and safeguard advocacy with patient and family views being fundamental to service review and development. This will include information sharing and communication issues both between professionals and service users.
- Be the driving force for planning, organising, delivering and reviewing clinical services and care for patients and their carers to ensure they are excellent, safe, efficient, up-to-date and sustainable.
- Act to reduce health inequalities and assure equity of access.
- Support the services provided, fostering a culture of collaboration, partnership, teamwork and learning.
- Enable commissioners and Trusts to enhance their clinical governance arrangements.
- Ensure uniform standards and appropriate care pathways are developed, implemented and audited across the network.
- Inform the decisions and processes for the distribution of resources to meet agreed standards and improve outcomes
- Minimise bureaucracy, simplify decision-making and ensure timely action.
- Have clear accountability and operational arrangements.

## **Implications for Practice**

## *A change agenda*

A major culture shift will be required amongst professionals as well as enabling the public to obtain a better understanding of the need for change.

The implementation of managed networks will require the full commitment of all involved.

In planning the shape of future services we need vision beyond this present professional generation – a twenty-year view. Clear objectives and milestones are essential for the management of change

Clinical practice is developing and new capabilities emerging. Arrangements need to be flexible and organic rather than fixed and rigid.

### **Children and families are central**

Needs of children/families must remain at the centre of all service planning and delivery – they need to be represented as an integral part of the network.

*Care must always be provided as close to home as possible, but if it is essential, and to avoid compromising standards of care, in certain circumstances, children will need to be cared for in specialist hospitals in other areas.*

‘Listening’, ‘hearing’ and communicating must be regarded as essential skills for improving patient focus, relationships with patients, families/carers as well as facilitating interaction between health professionals.

### *Standards are the bedrock*

Standards of care are the most important feature of a network. The commitment of all members is essential and once agreed, standards should not be optional but non-negotiable and mandatory.

In many specialties, specified standards do not currently exist and there is much work to do. Consistency is important between England and Wales and within Wales.

The extent to which it is possible to meet ideal standards immediately will depend on external factors such as staffing but the network must commit itself to a plan to achieve these as soon as possible.

When ever possible, standards should be based on evidence. This is not always available but commitment to seek, develop and apply evidence is essential.

### *Clinical governance*

Appropriate arrangements for clinical governance and accountability are crucial.

Individual members of networks have personal accountability for clinical performance through the chief executive of their employing body. The network will need to agree how its own collective approach to clinical governance is to be managed. External audit is becoming an increasingly important and valuable aspect of this process.

### **Management arrangements**

Strong clinical ownership of each network is crucial, as is clinical leadership. Overarching management arrangements and appropriate administrative support will need to be put in place.

Each network should have arrangements for external reference, peer review and quality assurance.

### *Owning and sharing resources*

The definition of the "centre of a network", a term widely used, is open to a number of interpretations. The child and family must be the single central feature. Their view of the most central elements of care may be different from those of professionals.

Clearly, some aspects of services may need to be provided together at a centralised point. Every member of the network must have access to these services. Working arrangements, to give this acceptable form, must be agreed through the network's operational plan. The key principle in its operation is that every member of the network is of equal value.

The whole resource, that comprises the clinical network, belongs corporately to all members of the team. All available resources must be used in an effective and efficient manner and will be aimed at a **service of excellence** in all elements of the network and its care pathways. Secondary care will have a pivotal role in directing children for tertiary care and ensuring those children's needs, including primary care and social settings, are addressed in full (bearing in mind that these are likely to be complex and will require co-ordination).

The identification and mapping of resources is a crucial component of network development. Resources are scarce and means will have to be found to identify and appropriately utilise all available elements within the arrangements. This is clearly a task for a network itself to address.

Some current working practices, such as on-call arrangements and bed ownership, mitigate against the most efficient use of resources and should be reviewed. Any apparent imbalances in distribution from one part of a network to another will need to be identified and dealt with.

Network collaboration requires all components to be functioning properly. If this is not the case then the network needs to work out corporately how to manage resources best (e.g. Paediatric Intensive Care is dependent on High Dependency Care)

Communication and modern information technology are essential infrastructure requirements.

### **Interactive service links**

Tertiary care is absolutely dependent on the quality and involvement of secondary and community based services.

Specialist care is interdependent with a range of other specialised and routine (such as investigative) services.

Children with rare conditions often have multiple needs and may require substantial elements of care from several sources, at any point on the care pathway. Wherever a child enters the service, geographically or in terms of the care pathway, he/she should be offered the same care standards. Specifying care pathways is crucial to the integrity of network development.

As children grow up, so the evolution of their care and the transition of their changing care and supporting needs into adulthood are important. Examples include cystic fibrosis, head injury, long term ventilation – and many more.

### **Professional concerns**

We need to find ways to value the contribution of secondary level paediatric practice as having an inherent specialism as other elements of care.

Every participant in a network needs to feel equally valued.

The value of mutual support for individual clinicians caring for very specialised complex and challenging cases should not be underestimated.

Training, teaching and a learning culture should be 'givens' for a clinical network. The links between service and academic (teaching and research) activity are important for both quality of care and for recruitment and retention of staff.

The sustainability of managed clinical networks is closely linked with medical and other workforce issues.

### **Conclusions and recommendations**

Managed clinical networks are a way forward – they need to be flexible and individually designed according to particular service needs.

The work SHSCW has commissioned is important and urgent but this does not take sufficient account of the 'vertical' networking requirement and needs to allow for primary care and secondary care network relationships.

Other areas of children's health care also need strengthening – 'generalist care; community and primary care – if tertiary care is to work properly.

There is sufficient work to be done around quality standards for a project in its own right across all paediatric specialties.

Infrastructure especially IM&T is prerequisite and every network will need a communications protocol.

Protocols should also address 'access'.

Extensive work on public involvement is needed.

This whole reform process amounts to major clinical redesign. It will need formal project management with an overarching steering group and full Prince type methodology – a 2-year time frame.

Investment will be needed in organisational and personal development. Clinical leadership skills should be fostered.

Network 'ownership' of fixed resources like beds/theatres/specialised kit needs to be explored and understood.

There is a need to be realistic about the future and accept that this is a major change agenda. The status quo is not an option.

Clinicians, with management support, will have to lead network development themselves - based on common ownership of the corporate resources and a consensus management style. External mentors and quality assurance arrangements will be needed.

### **Next Steps**

1. The process of developing Managed Clinical Networks for Specialist Paediatric Services needs to be put on a formal footing with the appointment of a project manager and the development of a funded project plan for implementation. The establishment of a Managed Network will require progress through a number of distinct stages:
  - Identification of members
  - Clarification of purpose
  - Establishment of standards

- Mapping resources
- Determining structure of service provision
- Identification of key external relationships
- Putting in place management arrangements
- Agreeing accountabilities
- Designing and implementing review and monitoring processes.

1. The process should be completed in two years but within that up to three specialties should be "fast-tracked", one of these should be paediatric neurosurgery to allow full consideration of the issues surrounding this service.
2. The Director of Healthcare Services for Children and Young People should be appointed to act as the "champion" in laying the foundations for a different approach to childrens' healthcare services in Wales. This appointment will be critical to the development of the All Wales "Institute for Child Health" in laying the basis for a comprehensive research network across all DGH and primary care based children's health care services.
3. Parallel work needs to be done to describe the accountability arrangements for networks, clinical governance arrangements, implications for the commissioning process, operational arrangements, network support and care pathways.

<b>Name</b>	<b>Title</b>	<b>Organisation</b>
Dr Ruth Hall	Chief Medical Officer	Welsh Assembly Government
Mr Mike Ponton	Director of Health and Well-Being Strategy and Planning Team	Welsh Assembly Government
Dr David Salter	Senior Medical Officer	Welsh Assembly Government
Dr Huw Jenkins	Senior Medical Officer	Welsh Assembly Government
Mr David Edwards	Chief Executive	Cardiff and Vale NHS Trust
Mr Ian Lane	Medical Director	Cardiff and Vale NHS Trust
Dr Mark Drayton	Paediatric Representative	Cardiff and Vale NHS Trust
Dr Graham Shortland	Paediatric Representative	Cardiff and Vale NHS Trust
Ms Jane Perrin	Chief Executive	Swansea NHS Trust
Mr John Calvert	Medical Director	Swansea NHS Trust
Dr Cathy White	Paediatric Representative	Swansea NHS Trust
Dr Jean Matthes	Paediatric Representative	Swansea NHS Trust
Ms Tricia Bochenski	Representative	Association of Community Health Council's  (Member of Clwyd CHC)
Dr Ian Bowler	Paediatric Representative	For Gwent Health Authority  (from Gwent Healthcare NHS Trust)

Dr Gwyneth Owen	Paediatric Representative	For Dyfed Powys Health Authority (from Carmarthenshire NHS Trust)
Dr Geraint Owens	Paediatric Representative	For North Wales Health Authority (from North East Wales NHS Trust)
Dr Paul Davis	Paediatric Representative	Bro Taf Health Authority (from Cardiff and Vale NHS Trust)
Dr Philip Edwards	Paediatric Representative	Iechyd Morgannwg Health Authority (from Bro Morgannwg NHS Trust)
Dr Gillian Todd	Director	Specialised Health Services Commission for Wales (SHSCW)
Mr Ian Barrington	Director of Children's Services	United Bristol NHS Trust
Mr Alan Sharples	Director of Finance	Royal Liverpool Children's NHS Trust
Mrs Angela Maguire	Patient Representative	
Mrs Margaret Foster	Representative	NACE
Prof. Julian Hopkins	Director of Clinical School	University of Swansea
Ms Cathy White	Health and Well-Being Strategy and Planning Team	Welsh Assembly Government
Ms Caroline Lewis	Health and Well-Being Strategy and Planning Team	Welsh Assembly Government
<b>Name</b>	<b>Title</b>	<b>Organisation</b>
Dr Ruth Hall	Chief Medical Officer	Welsh Assembly Government
Mr Mike Ponton	Director of Health and Well-Being Strategy and Planning Team	Welsh Assembly Government
Dr David Salter	Senior Medical Officer	Welsh Assembly Government
Dr Huw Jenkins	Senior Medical Officer	Welsh Assembly Government
Prof. David Hall	President	Royal College of Paediatrics and Child Health
Miss Leela Kapila	Representative	Royal College of Surgeons

Dr Peter Betts	Representative for Endocrinology	Southampton General Hospital
Dr Martin Brueton	Representative for Gastroenterology	Chelsea & Westminster Hospital
Dr Christopher Verity	Representative for Neurology	Addenbrooke's Hospital
Dr Sheila Mckenzie	Representative for Respiratory Medicine	Royal London Hospital
Prof. Graham Teasdale	Representative for Neurosurgery	Institute of Neurological Sciences, Glasgow
Mr F J Bramble	Representative for Surgery	Royal Victoria Hospital
Ms Cathy White	Health and Well-Being Strategy and Planning Team	Welsh Assembly Government
Ms Caroline Lewis	Health and Well-Being Strategy and Planning Team	Welsh Assembly Government

## Annex B

### Glossary of Terms

<b>TERM</b>	<b>DEFINITION</b>
<b>Advocacy</b>	The practice of representing a child or young person, of providing them with advice and support and conveying their needs and wishes to the appropriate authority. These may include befriending schemes, consultation processes, the production of public material on children and young people's rights and participation or the establishment of public forums.
<b>Care pathway</b>	The way the patient "moves through" different parts of the NHS and different agencies, such as social services.

<b>Child and family centred</b>	A system of care or treatment that is organised around the child and their family.
<b>Clinical audit</b>	A systematic examination of current practice to assess how well an institution or service is performing against set standards.
<b>Clinical effectiveness</b>	Giving patients the most appropriate care for a condition based on available evidence.
<b>Clinical governance</b>	A framework through which NHS organisations are accountable for continually improving the quality of their services and safeguarding high standards of care by creating an environment in which standards in clinical care will improve.
<b>Clinical network</b>	A network of health professionals working across traditional boundaries of health organisations in order to provide more effective care for patients.
<b>Commissioners</b>	The organisations responsible for purchasing services.
<b>Commissioning</b>	The process of identifying local health needs, drawing up plans with strategic partners to meet those needs, identifying appropriate health services and making agreements with health service providers to ensure that services are delivered.
<b>Community health services</b>	Health care usually provided outside a hospital, for example in the home or at school.
<b>Equity of access</b>	Access to the same standard of care regardless of geography, ethnicity and disability.
<b>Health inequalities</b>	The difference in health between different communities or groups within the population and is typically measured by mortality (death rates) and morbidity (levels of illness).
<b>Outcome of patient care</b>	The end result of a patient's treatment. This will include consideration of the quality of life, where a cure is not possible.
<b>Outreach</b>	A clinic or service provided close to where a patient lives by a clinician or team usually working in another location.
<b>Paediatrics</b>	The general medicine of childhood.
<b>Primary care services</b>	Services provided by family doctors, health visitors, practice nurses, dentists, pharmacists, optometrists and others in the local community - usually the first point of contact for patients.



<b>Providers</b>	The organisation that provides patient care, typically a NHS Trust or primary care.
<b>Quality Assurance Framework</b>	The definition of the principles that should be applied to ensure the quality outcome of a process or plan.
<b>Secondary care</b>	Services to which a patient is referred by family doctors, usually provided in a district general hospital.
<b>Stakeholders</b>	People and groups with an interest in the issue.
<b>Standards</b>	A level of quality by which performance can be measured.
<b>Specialised/Tertiary services</b>	Services which are best organised for large populations because demand for them is relatively small, cost of provision is high, and they call for high levels of expertise, often from centres of excellence.