Welcome to the fifth edition of the North West Tertiary Children’s Strategy Group Newsletter. This newsletter is primarily intended for colleagues in Primary Care Trusts (PCTs), Hospital Trusts, and service networks across the North West, North Wales, Isle of Man and neighbouring areas. To update you on the progress and developments across North West Children’s Tertiary Services.

This autumn edition aims to inform you on progress with regard to national and local work-streams within paediatric tertiary children’s services and networks; as well as showcase the excellent work being undertaken to improve Quality, Safety and Outcome measures. This edition also highlights the North West Tertiary Children’s North West & North Wales Network Conference, together with key updates on the National Safe & Sustainable work and the transition into the NHS Commissioning Board.

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NEWSLETTER HEADLINES:

North West & North Wales Network Conference

North West and North Wales: Conference: 6th October 2011

Five networks are coming together on the 6th October at Birchwood Park, Warrington to hold a joint conference day. This will bring together key participants with the opportunity to share their achievements and learning with each other. The key topics for the day will be:

- Networks Sharing of Good Practice / Achievements
- Transition of Care to the Community and to Adult Services
- National and North West Specialised Services / Network Perspective
- Trauma - The Future That Lies Ahead

The North West Networks involved are:

- Paediatric Critical Care
- Paediatric Long Term Ventilation
- Perinatal and Paediatric HIV
- Paediatric Burns
- Cleft Lip and Palate

All networks will have their own work programme for the afternoon session.

Registrations for this event will open in July and further details can be requested from louise.little@cmft.nhs.uk

Launch of the Commissioning Guide for Child and Maternal Health and Wellbeing


The guide is designed with children and families at its core. It gives a real focus to the importance of getting things right in the early years and to intervening early from pre-conception through to adolescence. It recognises that there are many influences on a child’s health and the quality of their lives, whether these are opportunities to play safely, communicate and learn, or explore new opportunities. The guide was produced with clinicians and professionals across health, local government and the voluntary sector, following consultation with children, young people and parents.

The guide is available free online and can be accessed at www.northwest.nhs.uk/childhealth

National Tertiary Children’s Services:

Safe and Sustainable Paediatric Cardiac Services

You will already be aware that the public consultation phase of the National Review of Children’s Congenital Heart Services in England was launched on Monday 28th February.

The consultation focuses on four options for the future configuration of children’s cardiac surgical services. The surgical centre for the North West, Isle of Man and North Wales - Alder Hey Children’s NHS Foundation Trust – features in all of the options. Consultation closed on the 1st July 2011.
A patient and public engagement event took place in the North West on Monday 9th May at the Halliwell Jones Stadium in Warrington. This event was extremely well attended and included a large audience of parents and young patients as well as NHS staff and commissioners.

Key issues raised by the audience for discussion included:
- The integration of children’s and adult services.
- Accommodation capacity at Alder Hey.
- Option scoring.
- How to ensure quality in all children’s cardiac surgery centres across the country.
- Impact of any change on cardiology services.

Discussions at the Warrington event, along with those from consultation events elsewhere around the country, will be collated by IPSOS Mori and fed back to the Joint Committee of Primary Care Trusts as part of the decision-making process in the autumn. In addition to the patient and public consultation event, a staff-only event took place at Alder Hey Hospital on May 12th. This event, which included nurses, clinicians and managers from across the North West Congenital Cardiac Network, was chaired by specialised commissioners and gave staff an opportunity to ask questions about the consultation and air any concerns.

With regard to the public consultation, nearly 60,000 parents, children and health professionals had their say. Over the coming months responses to the consultation will be analysed by an independent, expert third party. The Joint Committee of Primary Care Trusts (JCPCT) – the decision making body – will consider the feedback carefully and consider other relevant evidence. Additional information will be considered by the Joint Committee including detailed analysis from the Health Impact Assessment work, results from testing families’ travel patterns validated procedure numbers and Trusts’ detailed capacity planning information. In addition, an independent panel will consider the potential impact of the proposals on related services at the Royal Brompton Hospital and will provide advice to the Joint Committee.

The JCPCT is expected to make a final decision by the end of 2011. Implementation of any changes to children’s congenital heart services is expected to start in 2013. A detailed implementation plan will be developed once a decision has been made.

Paediatric Neurosurgery

The Safe and Sustainable Children’s Neurosurgical Services Review through the Safe and Sustainable Children’s Neurosurgical Steering Group, the Standards Working Group and the Models of Care Group have over the last two years all been working to establish a framework for Neurosurgical services in England for the future. The work has taken into account, clinical evidence; best practice in key areas and has consulted with a wide audience to develop this work.

In addition, the groups have considered the recent NHS Clinical Advisory Group guidance for the Management of Children with Major Trauma, which sets out the requirements for children’s neurosurgery in providing care and support to the child with a major head injury, most importantly that paediatric neurosurgery consultants should be available for consultation and care to the Trauma Network 24/7. The recently launched ‘Head Smart’ campaign aims to reduce the time it takes to diagnose children and young people with brain tumours in the UK raising awareness about the signs and symptoms for carers and professionals. Children in the UK with a brain tumour may take up to three times longer to be diagnosed than children in other countries.

The National Steering Group considered that on balance evolution via a managed network approach comprising all current paediatric neurosurgical centres is the best way forward. By
working closely together in a managed network the best use of rare specialist expertise can be optimised to improve care and access. This should provide coherence and integration from the parent and family perspective, from presentation, diagnosis, treatment, after care and finally ongoing support at home and at school.

The Safe & Sustainable Team has circulated the two attached documents for comment:

- Children’s Neurosurgical Specification Standards, May 2011

All comments will be reviewed by the Steering Group at its meeting in the autumn prior to finalising the documents which will go out for wider comment.

Please send your comments by email to child.neuro@london.nhs.uk or direct to:

Stephanie Stanwick,
Safe and Sustainable,
National Specialised Commissioning Team,
2nd floor, Southside,
105 Victoria Street,
London
SW1E 6QT

All comments should be received by 16th September 2011

North West/North Wales Children’s Clinical Networks:

North West & North Wales Paediatric Transfer Service (NWTS)

The NWTS Team (The North West and North Wales Paediatric Transfer Service) has now been operational for just over 6 months.

Since going live in November, the NWTS referral line (08000 84 83 82) has taken over 600 calls and the team has undertaken 379 retrievals to date.

The NWTS Team have been involved in the following:

1. Presenting at both the Paediatric Neurosurgical Study Day at Alder Hey and the Welsh Paediatric Anaesthetic Meeting.
2. Outreach education – reaching 16 of our 31 DGHs.
3. Simulation, training has been undertaken at NWTS base, at outreach sessions and even in the back of our ambulance.
4. Presenting at both of our Lead Centre Grand Rounds
5. Collaboration with the PCCN to develop regional guidelines

The Team also ran its own one day conference at Birchwood Park, Warrington on May 26th. This was a great success with over 80 delegates from across the region. The conference theme was ‘Dealing with Sudden Death’.
The programme included lectures on why children die and organ donation. A lively debate was held asking the question

“Preserving Life- is quality of life a sufficient argument?”

**North West & North Wales Paediatric Long Term Ventilation (LTV) Network**

**Non Invasive Ventilation Services**

A report was due in July 2011. The aim of this work is to address two main issues:

- To improve communication and timeliness of decision making processes within the Non-invasive ventilation pathway of care.

- To provide a safe, cost effective solution for non-invasive ventilated patients in the community with regard to access to equipment, consumables and on-going maintenance. To move away from current spot purchasing solutions which currently causes delays in the patient pathway which may only intensify once the current PCT commissioning arrangements change.

This work proposes a way forward for PCT Commissioners consideration to provide a safe, consistent co-ordinated approach to the discharge process, purchase and maintenance of equipment as well as ensure support for breakdown or repair of equipment is in place. The on-going supply of consumables will also need to be addressed.

The aim is to establish an agreed approach across the North West to reduce delays in the commencement of treatment as well as remove the delay in requesting and approving treatment.

The first stage of the work can be viewed at the following link: [http://nww.nwsct.nhs.uk/Docs/NWSTCGS/Newsletter/Attachments/2011/NWNIVproposal.pdf](http://nww.nwsct.nhs.uk/Docs/NWSTCGS/Newsletter/Attachments/2011/NWNIVproposal.pdf)
The NW Perinatal and Paediatric HIV Network has been working hard to move forward with its core objectives including work around transition from paediatric to adult services. Transition was the focus of the Network’s fifth Engagement Event which took place in February 2011. The event gave children and young people who receive care from HIV health services the opportunity to come together with professionals and clinicians from the HIV field.

Eighteen young people from Manchester, two from Liverpool, two from Staffordshire and one young positive speaker (aged 21yrs) attended along with over 10 professionals. The day started with some fun “ice breaker games”. This was followed by a presentation from peer support group members who summarised the findings from a pre-event questionnaire completed by the majority of Manchester/Liverpool young people. The questionnaire (designed by Katie Rowson, Paediatric Specialist Nurse, North Manchester General Hospital) enabled the young people’s thoughts, ideas and feelings about transitioning from children’s clinics to adult services to be captured in order to influence the development of Transition Clinics in their areas. Outcomes included the agreement that clinics specifically for young people are needed and that if this was not practicable that teenagers should at least be grouped together. Young people want clear explanations in relation to their health and not medical jargon and they should know their diagnosis and be mature and confident enough to be seen alone (without parents/carers).

There was also an ever popular ‘Expert Panel’ which included an HIV positive young man who has experience transitioning in a London clinic, an HIV specialist paediatric and HIV specialist adult nurse along with an adult and a paediatric HIV specialist doctor. The panel fielded numerous questions about what it was like to be HIV positive, what impact it has on where you can go and what you can do and how it feels when other people don’t understand.

Feedback was very positive from all who attended. Thanks as usual go to the Barnardo’s Gregory’s Place team who organized and facilitated yet another successful engagement event.

A huge amount of work has also been done on developing a transition ‘passport’ which is a summary of the patient’s care that will go with the patient as they move from paediatric to adult services. This document has now been circulated widely across the Network and will also be cascaded to the adult sexual health networks.

The implementation of the paediatric HIV business case in North Manchester General Hospital is making further progress. The recruitment to the HIV Family Team based in North Manchester General Hospital is nearly completed. The appointment of the Clinical Psychologist is the only outstanding appointment. The Baby Clinic has recently been increased to weekly clinics and meetings to set up a Transition Clinic have taken place. It is hoped that this can be established later this year.

Finally the Network has recently signed off its work programme for the coming year which includes objectives to:

- Strengthen and maintain links with other HIV and Sexual Health Networks
- Continue to monitor antenatal HIV screening rates
- Oversee the implementation of a transition pathway
- Develop an audit re: psychological/social support

The latest NW Perinatal and Paediatric HIV Network Newsletter can be viewed at the following link:
North West Neuromuscular Service Review

There has been a lot of interest in the North West Neuromuscular Services Review Document – ‘Our Future Services’ since it was received at the meeting of the NWSCG at the end of March 2011. This has included considerable political interest from local MPs, the Muscular Dystrophy Campaign, Patient Groups and individuals who continue to lobby for better neuromuscular services. These key stakeholders have been assured that the NHS in the North West is doing all it can to drive improvements for these patients taking into account the context where there are many competing interests all of which have to be balanced in a fair and effective way.

At the NWSCG meeting following discussion it was recommended that the report should be sent to Primary Care Chief Executives for circulation to respective Board members and GP Commissioning Consortia Leads for their view. Feedback to NWSCT from these meetings is currently being sought which may help to support and inform an implementation plan across the North West.

The responsibilities outlined within the report highlight potential savings which may be realised by associated QIPP plan to support future service planning. In order to contribute to potential savings the PCTs/GP Commissioning Consortia are recommended to focus on strengthening their community pathways for patients with long term and complex conditions to include neuromuscular patients who until recently have not had equitable access to these services. NHS Manchester and Central Manchester University Hospitals NHS Foundation Trust are looking at a pilot which by utilisation of existing resources and better integrated working between the community and tertiary services will support delivery of better care for neuromuscular patients.

In addition to the above, a National Neuromuscular Review is currently being undertaken by representatives from the 10 SCGs across the England to address review commonalities within service areas. A national approach will ensure standardised service delivery ensuring quality, equitable and safe services for all neuromuscular patients. The North West and South Central SCGs are working together to ‘Understand and identify opportunities for better utilisation of the current workforce models of care within the community and their links/integration with the Trusts and the specialised Neuromuscular Disorder providers.’ The focus is on physiotherapy and community nursing team provision and the review and report will be completed by the end of September 2011.

North West Children’s Cancer Services: Implementing the NICE Improving Outcomes Guidance for Children & Young People?

The NICE Improving Outcome Guidance for Children and Young People with Cancer published in 2005 has been a priority work stream for the North West Cancer Networks, Specialised Commissioners, PCT commissioners and providers of services with full implementation completed by 2010/2011.

The guidance covering the children’s element of the document was translated into a set of measures which were published in November 2010 to enable services to assess their performance. The process by which services are audited against the measures is Peer Review and consists of self-assessment, internal validation followed by an external review.

This guidance did not follow the usual format for site specific tumour groups as it was age and not tumour site specific and was the first of this type of guidance to be implemented. It therefore presented many challenges for the North West including specific measures for the Specialised
Commissioning Group with expectations of a commissioning strategy for children with cancer which did not align with the strategic vision of the organisations in the North West. With this in mind the implementation teams worked hard to balance the requirements of the measures with the commissioning, policy context and changes occurring in the NHS currently.

An external National Peer Review team has recently (May 2011) assessed compliance against the measures for the Lancashire and South Cumbria Cancer Network and the NWSCG. It was acknowledged that considerable work has been undertaken to work towards compliance and to deliver safe, effective, equitable and patient centred services. However it identified that work still needs to be done to further develop shared care arrangements in the north of the region and the NWSCG need to work together with the children’s cancer network group to develop a strategy to ensure the driving forward and sustainability of children’s cancer services for the future. This work is continuing and an implementation plan will be communicated to the National Peer Review Team by June 2011.

The Peer Review process for the Teenagers and Young Adults element of the Improving Outcomes Guidance has just commenced with publication of the draft measures in January 2011. The final measures are expected to be published in the next few weeks following a three month consultation period and feedback process following publication of the draft measures. Work has already commenced across the North West to collate evidence for Peer Review.

**Zonal Neonatal Intensive Care Networks**

**Greater Manchester Neonatal Intensive Care Partnership**

Progress is continuing towards the first major element of the reconfiguration of neonatal intensive care provision across the Greater Manchester conurbation. Under the ‘Making it Better’ programme, new neonatal intensive care units are being developed at the Royal Bolton Hospital and at the Royal Oldham Hospital. These will replace the existing NICU on the Salford Royal site, and will operate alongside the existing NICU at St Mary’s in central Manchester.

A comprehensive programme of staff recruitment has been undertaken, to include both medical and nursing staff. A nurse development programme has also been implemented to ensure that the nursing staff who will work in the new NICUs have the appropriate skills. A nurse rotation programme has also been implemented to give Royal Bolton and Royal Oldham staff experience of working in a NICU environment before their own unit is formally re-designated.

The capital build at Royal Bolton is on schedule to be completed in the third quarter of 2011, with the unit being ready to take on its new role when the existing unit at Salford Royal is decommissioned in November.

The capital build at Royal Oldham is on schedule to be completed in the fourth quarter of 2012, at which time the neonatal intensive care activity across Greater Manchester will be realigned between the three NICUs, bringing the service closer for the majority of the population.

**Cheshire & Merseyside Neonatal Network**

All Networks have been asked to contribute to the PCT cost savings by reducing the funding requirements. So far the Cheshire & Merseyside Neonatal Network has reduced the budget by 30% achieved from reducing Training contributions for the induction programme. This imposes more of a pressure on the provider Trusts to enable new staff to attend the training and be released to undertake the required placements for Intensive Care and High Dependency experience. If Trusts cannot support this then the previous recruitment and retention issues may
return again in the future and this must be monitored. The programme was a great success and it would be detrimental to workforce succession planning to lose the advantage the Networks have experienced since the programme commenced.

The Network is delighted to report that the Neonatal Transport service is expected to be operational 24 hours a day 7 days a week as of September 2011. Medical staffing has proved a challenge however a workable solution has been found.

Designation is expected to progress to the next stage in October 2011, once the Transport Service is in place, aiming for babies less than 27 weeks gestation to be delivered or receive Intensive care in a Neonatal Intensive Care Unit (NICU)

Family and Babies Support (FaB Support) has been rolled out and is at various levels of implementation in six of the Neonatal Units. The other two are being encouraged to progress with this. This initiative has proved a great success on the Wirral where the pilot project was developed. It encourages children’s centre family support workers to become involved with all families at an early stage to provide support and links to any additional services that may be required.

It is planned to hold an event to share information amongst the staff who are involved of good practice to how to avoid repeating failures. Once information is gathered and all units are involved it is intended to align data collection showing the output and success of the project and launch it at a national event.

The Education group have focussed on areas of the Toolkit to develop information packages which can be implemented within each unit to meet guidance on developmental care, bereavement support, pain management, discharge planning and a parent communication pathway.

Parents have now been recruited as network board members and a group established.

Projects prioritised and currently in progress are:

- Reviewing Allied Health Professional access for Neonatal services.
- Developing Palliative Care pathways.
- Review of Medical staffing issues.
- Processing data for implementation of HRG4.
- Improving data quality for local and national use.
- Pathway development.
- Audit programme.

Nationally there is a service specification in development and a Neonatal dashboard which are expected to be implemented in April 2012.

**Lancashire & South Cumbria Neonatal Network**

All Networks in Lancashire & South Cumbria have undertaken several reviews on how to reduce costs of Networks and explore ways to collaborate. This work is still ongoing and no final decisions have been made. There has been a total freeze on posts which has left the Neonatal Network with only a half time director, full time PA and Lead Nurse one session per week, who is leaving at the end of June.

This has had a serious impact on output of the Network over the past two years. With all the added time spent reviewing current structures and attending meetings on future plans, actual time to progress with work programmes is severely diminished.
The Network has progressed with designation however and all trusts have signed up to have babies less than 27 weeks gestation receive care in a NICU. There remain concerns regarding quality payments via NWSCT for NICU services and local PCT pressures.

Family and Babies Support (FaB Support) has been rolled out and is at various levels of implementation in all of the Lancashire & South Cumbria Neonatal Units.

The Education group have also been working on developing packages for units to address national guidance on pain management, pain management and discharge planning, bereavement and palliative care support. A study day is planned for later this year and the Network is hosting the Annual PREMNW meeting.

Data is a focus for the Network currently with 2 days per week of analyst time purchased via CBS to:

- Process information for implementation of HRG4.
- Improve data quality for local and national use.
- Establish an audit programme

* A joint Website is currently in production and is expected to go live within the next 2 weeks.

**North West Cleft Lip and Palate Network**

**North West of England, the Isle of Man and North Wales Cleft Lip & Palate Network**

The Network is pleased to announce that Simon van Eeden has taken over as the Network’s Clinical Director as of the 1st June 2011. Simon is a Cleft Surgeon based at Alder Hey Children’s Hospital and has some exciting ideas about what he would like to do over the next three years. The Network would also like to thank Joyce Russell, its previous Clinical Director, for the outstanding work she has undertaken over the last six years to establish the Network and to enhance cleft services for our patients and their families.

Network members have recently joined together to re-assess what its future priorities are so that we can develop new objectives. The top five priorities identified are as follows:

- Patient Experience and Information
- Transition
- Outcome measures and Audit
- Information and data collection
- Research and Development

We already have working groups considering Patient Information and Transition. The Patient Information Group has completed its first ‘list’ of leaflets and is about to embark on the next tranche including looking at information aimed specifically at children rather than just at parents. The Transition group has already undertaken a literature review and an information gathering exercise looking at what other services are already doing and is now planning a scoping exercise to see what teenagers with clefts want and need when moving to adult services.

Over the last six months the Network has continued to monitor diagnosis and referral rates for babies born with clefts and has been in discussion with maternity and scanning units which are performing well in order to understand their practices so that this can be shared with other units.
We have also completed the Annual Clinical Audit Report for 2010/2011 and this has now been circulated widely to the Network, to the Tertiary Trusts and to colleagues in the North West Specialised Commissioning Team.

The Cleft Lip and Palate Annual Report is also nearing completion and this too will be circulated widely. The Network is also intending to produce a user-friendly version of this report to send out to patients and families.

**North West Tertiary Children’s Network Transition**

With regard to the future provision of networks with clear governance structures, discussions have taken over the last six months with respect to the continuity arrangements for the three tertiary children’s networks that the North West Specialised Commissioning Team (NWSCT) have been supporting. It has been agreed that the two tertiary children’s trusts; Alder Hey Children’s NHS Foundation Trust and Central Manchester University Hospitals NHS Foundation Trust, will be taking the networks forward. From 5th April 2011, new management arrangements are in place for North West & North Wales Paediatric Long Term Ventilation Network, the North West Perinatal and Paediatric HIV Network and the North West & North Wales Paediatric Critical Care Network. The new arrangements will add value in strengthening the platform from which the Networks can continue to successfully develop and improve service provision.

If you have any queries or would like further information about the Tertiary Children’s Strategy Group please contact Sue Bell (Programme Manager) - sue.bell@nwsct.nhs.uk.

We aim to develop the newsletter over the coming months. If you have any suggestions about how we can make this newsletter relevant to you, or if you have any comments on the newsletter with regard to format please contact Rosemary Ashtonhurst on rosemary.ashtonhurst@nwsct.nhs.uk

Please visit our NHS internal website for more information: [nww.nwscg.nhs.uk](http://nww.nwscg.nhs.uk)