

+ Meeting Notes - 09.11.2018

Participants

- Graham Smith (GS)
- Pugazh Kandaswamy (PK)
- Michelle James-Ellison (MJE)
- Torsten Hildebrandt (TH)
- Shiv Hegde (SH)
- Aoife Owens

Apologies

- Raj Krishnan (RK)
- Judith VanDerVoort (JvV)
- Toni Williams
- Markus Hesseling

	Agenda Item and action	Action by
1	Welcome and apologies	
2	Minutes of last network meeting – agreed as accurate. Matters Arising – all in agenda.	
3	<p>Peripheral clinics</p> <p>Discussions were had regarding the following peripheral clinics:</p> <p>Bridgend: Reorganisation of Health Boards means that Princess of Wales Hospital will move from Abertawe Bro Morgannwg UHB to Cwm Taf UHB. This should not disrupt the paediatric nephrology clinic but it is still unclear as to whether there will be significant impact on in-patient workload.</p> <p>TH does not yet have access to Vital Data and he will chase this up with Gary Hunter at UHW.</p> <p>Morrison: The Morrison clinic remains busy taking place every 4 months alongside recently introduced 6 monthly transition clinics. GS acknowledges the work created for MJE by the complexity of some of these patients. Vital Data is installed on MJE's computer and the computer in the clinic room at Morrison.</p> <p>Neville Hall: GS and PK are building the clinic serving patients in Gwent. This too takes place 4 monthly. Vital Data is installed on PK's computer and the computer in the clinic room at Neville Hall.</p> <p>Hywel Dda: Clinics currently take place in Carmarthen/Withybush (JvV) and Aberystwyth (RK). The move to bring these patients together into one clinic are progressing.</p> <p>Cwm Taf: Neither JvV or Ezzat Afifi were not present. They currently run this clinic in Ysbyty Cwm Cynon, Mountain Ash.</p> <p>Discussions were had about the benefits of seeing patients in peripheral clinics. Number of factors involved:</p> <ul style="list-style-type: none"> • Clinical complexity of patient • Relative ease of access of local hospital and UHW e.g. transport links, distance • Cost to families 	<p>TH</p> <p>RK JvV</p>

	<ul style="list-style-type: none"> • Time available to local staff to take on extra work created by increasing proportion of patients seen locally • Desire to maintain familiarity of patients to local staff who may be involved in emergency care <p>These will need to be looked at for the individual patient / family.</p> <p>It is disappointing that the recent meetings with WHSSC seems to have faltered without any apparent resolution of the issues raised, particularly the transparency of the flow of money defined by WHSSC for the funding of the Welsh paediatric nephrology service.</p> <p>TH raised the issue of identifying the workload / number of patients. GS explained that patients registered on Vital Data could be extracted using any of the variables collected for each patient. It might be useful for local paediatricians with responsibility for nephrology cases to collect data on the number of patients seen. This should be restricted to the children who would fall outside the remit of a general paediatrician. It would not be unreasonable to register such children on Vital Data.</p>	
4	<p>Transition to Adult Care Clinic Proposals</p> <p>Discussions took place on the transition program in South Wales. North Wales was not represented at the meeting and have a different program based on guidance from the Alder Hey team. Information on both programs is available on the WCNPN website.</p> <p>Two young adult clinics are now taking place in South Wales, one in UHW and the second in Morriston Hospital.</p> <p>The first clinic at Morriston took place in August 2018 with a second in January. The relative infrequency of this clinic means that some patients will need to continue to attend the paediatric clinics until they are ready to move to the adult clinic.</p> <p>SH holds a young adult clinic in UHW with Dr Sian Griffin which has been taking place for many years. It is held monthly and SH reports that it has become very busy.</p> <p>Which of these two clinics patients will move into is primarily determined by the site of their adult follow up. Adult nephrology services in South Wales are based in Cardiff and Swansea with satellite services. Patients from Hywel Dda will be incorporated into the Morriston clinic and those from Aneurin Bevan into the UHW clinic. If the peripheral clinic in Neville Hall grows and with the ultimate rationalisation of services in Gwent it may be possible to set up a young adult clinic in the future. Some thought will need to be given to the process for those children currently being seen in Bridgend. Similar issues affect patients being seen in Ysbyty Cwm Cynon although the adult service in Merthyr is run by visiting UHW nephrologists.</p>	TH

	<p>It is important to recognise that the transition process starts well before the move to a young adult clinic. Using the ReadySteadyGo program we aim to start at around 13/14 years of age. This transition process has been dramatically improved by the appointment of Shaun Thomas, our youth worker. On the back of the demonstrable improvement in patient outcomes it is hoped to appoint to a second similar post. Discussions took place on how we could improve the transition journey. The ReadySteadyGo program uses a template only available in a paper version which currently sits in the patient's notes. It was felt that this sometimes becomes a tick box exercise and there is rarely enough time in clinic to explore the issues that need to be discussed. Development of more user-friendly forms of providing information to teenagers was felt to be required. The ReadySteadyGo program is a generic one not specific to renal patients. Future developments therefore need to involve all paediatric teams looking after children with chronic diseases. In order to try and take these thoughts forward a number of proposals were made:</p> <ul style="list-style-type: none"> • Ask patients who have been through or are going through the transition process to provide insight into what would help them. This could be co-ordinated by Shaun Thomas. GS will talk to Shaun. • Identify if there are suitable resources already available. • Look at how we might be able to initiate the development of an App to support patients in the transition process. Given the applicability of such a resource to all children with chronic disease GS did not feel that identifying funding to support such a development would be a problem if it is possible to engage other specialties. • Organise a study day looking at transition to which all staff who have contact with patients undergoing transition (paediatric and adult) in all specialties e.g diabetes, epilepsy, inflammatory bowel disease etc. plus patients to discuss these issues. 	<p>GS</p> <p>GS</p>
5	<p>Psychologist appointment</p> <p>GS informed the group that a dedicated psychologist has been appointed to the renal unit in Cardiff. Nicole Parish, who has been working with us for a while now, should now be able to provide significantly more psychology support to our patients with fewer limitations on her practice.</p>	
6	<p>Structure of future meetings</p> <p>There was a relatively small turn out to the meeting. It is important to maintain interest in the network activities but obviously there is a significant amount of competition for people's time.</p> <p>It was proposed that the next business meeting will be through an interactive forum, possibly Skype for Business. TH and GS will look to identify the system which can be best utilised by all interested parties. It does not need to be an NHS Wales based system as there are no security concerns.</p>	<p>GS TH</p>

7	Involvement of Urology It was agreed that further efforts should be made to open the group up to our urology colleagues. If this is successful consideration should be given to renaming the network the Welsh Clinical Network for Paediatric Nephrourology.	GS
8	Website There was agreement that the website provide useful information for staff.	
9	Guidelines Guidelines are available on the website and the scope of the guidelines will be expanded.	GS
10	Paediatric nephrology Studies and Research SH reported on the studies currently being recruited to: <ul style="list-style-type: none"> • PREDNOS2 • NephroS • ECUSTEC They are being co-ordinated by SH and further information can be obtained by contacting him. GS will put a page on the WCNPN website about the ongoing studies. SH will present the results of the PREDNOS study during the study day. Welsh patients were part of this important trial.	GS SH
11	Audit MJE and PK are looking at a study of renal stone disease in Welsh children. PK has spoken to paediatric urology colleagues who are keen to be involved. This could be run through the WPSU.	MJE PK
12	AOB Nothing raised.	
13	Next meeting The next business meeting will be via interactive technology. Date to be confirmed. The next study day will be based around transition. Date to be confirmed.	