

# + Meeting Notes- 03.08.2017

## Participants

- Michelle James-Ellison (MJE)
- Katherine Wooding (KW)
- Graham Smith (GS)
- Shivaram Hegde (SH)
- Saurabh Patwardhan (SP)
- Pugazh Kandaswamy (PK)

## Apologies

- Jaya Natarajan (JN)
- Madalitso Kubwalo (MK)
- Toni Williams (TW)
- Torsten Hildebrandt (TH)

## Via video link

- Markus Hesselning (MH)
- Judith VanDerVoort (JvV)
- Raj Krishnan (RK)

	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>Constitution</p> <p>ii. Review of constitution</p> <ul style="list-style-type: none"> <li>- Discussion. As paediatric nephrology in North Wales is organised around tertiary service provided by Alder Hey, should this be a South Wales Renal Network or All Wales Network (MH)? Group clarified the purpose of network. CYPSS and NSF were starting point or basis for network and derived as all Wales documents. Focus of group is all children in Wales and all Wales standards of care. Commissioning body WHSCC is the same across Wales. (RK) all other networks serve all Wales. (GS) Recent meetings and current WSHCC Paediatric Nephrology discussion involving all Wales support view that it should be a Welsh clinical network. Funding money and standards unite group across Wales. WSHCC must be influenced by and informed of Welsh children's needs in North Wales. All Wales constitution would give clarity for WSHCC (JvV). Feedback to e.g. WHSCC should include All Wales matters (South and N Wales). Presence and involvement of CD (Keiran Donovan) for adult renal network is opportunity. (RK) Adult Renal Network is a funding body – also Paeds Nephrology benefits re governance and risk identified by RK. (KW) Noted experience of Paediatric Oncology is that funding streams aligned to adult services have better voice and better chance of success. There may be opportunities to compare and contrast services and delivery and benefit and learn from variations in practice in North vs South Wales (SH)</li> <li>- Agreement from meeting members for all Wales network – recognizing and mindful of North Wales organization. Constitution needs to be explicit that NW is organised differently from South.</li> </ul> <p><b>1. Write a paragraph for NW in constitution for All Wales Network MJE and MK.</b></p> <p><b>2. Inform and forward draft constitution to WHSCC Women and Child Health Clinical Lead- Dr Helen Fardy in time for Sept 7<sup>th</sup> meeting WHSCC.</b></p> <p>ii. Officers to be appointed</p>	<p>MJE and MH</p> <p>MJE</p>

	<ul style="list-style-type: none"> <li>- Chair – MJE has served from 2014 – 2017 (current) and term is for 3 years. Chair best suited for Paediatrician with experience i.e. not new in post.</li> </ul> <p><b>3. Suggested to approach Dr Torsten Hildebrandt POWH for Chair from 2018.</b></p> <p>If Dr Hildebrandt not a contender then ask UHW Renal Cons to chair for next 3 years or possibly Dr Affifi.</p> <ul style="list-style-type: none"> <li>- Dr Pugazh Kandaswamy to be network sec as Dr Hari Bodla (previous secretary) has emigrated. Proposed (GS) and seconded (MJE) - appointed.</li> </ul> <p>iii. Patient engagement</p> <ul style="list-style-type: none"> <li>- important part of network and a must to inform and direct network activities. WSCHH enquired about this.</li> <li>- Suggestions or examples in other areas? (KW) SW programme and ABMUHB Changing for the Better (C4B) work had patient engagement in decisions via Children in Wales. Network activities must reflect and centre around patients needs. WKPA and RCPCH potential for patient engagement</li> </ul> <p><b>4. WKPA – engagement explore via GS</b></p> <p><b>5. RCPCH ask advice from their group MH</b></p> <p><b>6. Speak to Children in Wales and Diabetes Network about engagement MJE</b></p> <ul style="list-style-type: none"> <li>- G Smith is going to write on his OP letters inviting patients to get involved</li> <li>- (RK) patient experience questionnaire available or RCPCH website and can be modified for feedback from clinics. He will explore use/ appropriateness and contact patients in Transition in Cardiff RJ explore.</li> <li>- Education/ study day could include family/ patient (patient story?)</li> </ul> <p><b>vi. Constitution Sign off needed – MJE recirculate once done.</b></p>	<p><b>MJE</b></p> <p><b>GS</b></p> <p><b>MH</b></p> <p><b>MJE</b></p> <p><b>MJE and All</b></p>
<b>4</b>	<p>Peripheral Clinics status – presentation by GS Slides (GS)</p> <p>Links</p> <ul style="list-style-type: none"> <li>- Cwm Taf HB: Dr Ezzat Afifi</li> <li>- ABHB: Pugazh Kandaswamy</li> <li>- Hywel Da: Toni Williams</li> <li>- ABMUHB: Torsten POWH</li> <li>- ABMUHB: Michelle J-Ellison Morriston</li> <li>- Betsi Cadwallader HB: Glanclwyd Dr Markus Hesseling</li> <li>- Betsi Cadwallader HB: Dr Madalitso Kubala</li> <li>- Betsi Cadwallader HB: Dr Nick Nelhans</li> </ul> <p>Key Points of talk</p> <ul style="list-style-type: none"> <li>- Families to have clinics nearer home</li> <li>- Aspire to increase frequency tertiary clinics</li> <li>- must explore what serves patients best.</li> <li>- Tertiary Health professionals in peripheral clinic</li> <li>- Enhanced IT needed spread of VitalData electronic results and drug records in South Wales</li> <li>- Costs of bloods repatriated</li> </ul>	

	<ul style="list-style-type: none"> <li>- Time for Local Link in Job plan for renal work.</li> <li>- GS – 3y clinics should be accessed via local clinic in link first screened.</li> </ul> <p>Discussion</p> <ul style="list-style-type: none"> <li>- Not all Paeds renal work is done by Paeds with interest/ link Paeds DGH Paeds see many children with renal problems. Variable skills of DGH Paeds and access. MH GlanClwyd peripheral clinic owned by local Paeds with interest. Opportunity to discuss patients and yearly talk to Paeds dept (education) with visiting Alder Hey Paediatric Nephrologist.</li> <li>(SP) Carmarthen and Bronglais q 6 monthly clinics potential for combining clinic patients to reach a critical mass.</li> <li>(MJE) Paeds nephrology in DGH overlaps between secondary and tertiary. WSHCC only funds tertiary care.</li> <li>- Question how much tertiary support needed (SP) in peripheral clinic? (SH) how much tertiary support/ can be replicated in DGH? Is there published guidance on e.g. support for DGH clinics in terms of sessions? Any info about time or funding. (SH) Scotland Paeds Renal network has guidelines when to see tertiary Paeds renal specialist</li> </ul> <p><b>1. Explore published (referral) pathways and criteria for 3y renal services e.g. Scots Network SH and GS.</b></p> <ul style="list-style-type: none"> <li>- JvV doing work on primary and secondary care interface Cardiff with a QI leadership fellow i.e. what paediatric services can be done in primary vv 2<sup>y</sup> care. Could make a leadership fellow bid to look at Wales DGH 2<sup>y</sup> vv 3<sup>y</sup> renal.</li> </ul> <p><b>2. JvV to share primary and secondary care algorithms and work with GS. Plan for a Paeds renal QI Leadership fellow proposal.</b></p> <ul style="list-style-type: none"> <li>- Data for WSHCC via RK gross numbers seen in peripheral clinics. WSHCC interested in tertiary services only. (KW) difficult task - oncology took long time to unpick and answer this question. Suggest network establishes what are DGH vv 3y patients seen in clinics in order to explain to WHSCC. Need information to support any request for additional funding, bloods, admin support.</li> </ul> <p><b>3. Audit of DGH's what renal patients do they see in OP clinic – renal conditions, cases mix, CKD</b></p>	<p>SH and GS</p> <p>GS and JvV</p> <p>MJE GS PK and MH</p>
5	<p>Transition to Adult Care Clinic Proposals</p> <p>GS presented slides – included Ready steady go transition framework (on website).</p> <p>Discussion</p> <ul style="list-style-type: none"> <li>- NW transition 1 -2 per year from Glan Clwyd. Adult nephrologist attends last clinic and then next clinic with adult. Adult nephrologists working in all 3 North Wales hospitals. Transition running 10 years plus in UHW; (SH) think Paeds managers unaware of value of transition for children with chronic disease. Adult nephrologists and adult renal network lead and WSCHH do.</li> <li>- Preliminary talks with Dr Clare palmer Adult Nephrologists at Morriston – for es-</li> </ul>	

	<p>establishing Transition Clinic for West Wales young people (with CKD transplant etc). Preparation to start after age 14 years?</p> <p><b>1. Get all Wales data 14 years and above to look at unmet need for Transition Clinics in Wales (for WHSCC). MJE to contact TW, EzAf re transition data</b></p> <p><b>2. PK to look at numbers for ABHB to see if potential for transition clinics there</b></p> <p><b>3. MH look at NW transition potential numbers</b></p>	<b>PK, MH and MJE</b>
<b>6</b>	<p>Website (GS) talked thru. Accessible anywhere. Set up via NWYS. GS manager. GS formally thanked for his work, innovation and skill.</p> <p>Discussion</p> <ul style="list-style-type: none"> <li>(MH) transition site accessed by families so should not be SW centric - NW too. Ensure website reviewed by Nick Nelhans Madalitso Kubala and Markus plus Henry Morgan Paeds from Alder Hay.</li> </ul> <p><b>1. GS to email website link –to them for feedback</b></p> <p>PatientView is on website. In UHW (SH) adult patients view their HB data. Risk of data theft so they have to agree. No formal mechanism for Paediatrics but SH gets signed assent from parent. All agreed that assent needed. Data governance rules.</p> <p>(MH) – does NWYS know that website contains PatientView? GS will check.</p> <p>Website co-owner needed – agreed by GS and all</p> <p><b>2. SH to check re assent for access to PatientView and check with NWYS about acceptability of PatientView being available on website with assent.</b></p> <p><b>3. Ask Torsten to be co-owner of website</b></p>	<p><b>GS</b></p> <p><b>SH and GS</b></p> <p><b>GS</b></p>
<b>7</b>	<p>Guidelines on website</p> <ul style="list-style-type: none"> <li>Tertiary guidelines are not North Wales guidelines as North Wales hospitals aligned with Alder Hey (MH). UHW guidelines clear disclaimer in front – all agreed adequate disclaimer. JvV who updates guidelines? Ownership and access to putting on guidelines discussed.</li> <li>Local DGH guidelines. Governance and governance review differs (PK) local guidelines have local governance and differs from HB to HB. PK has developed local guidelines have hyperlinks to UHW guidelines</li> </ul> <p><b>1. Plan to divide guidelines page clearly identified into a DGH area and tertiary guidelines North or South</b></p> <p><b>2. Share appropriate DGH guidelines with group for further discussion and inclusion on website</b></p>	<b>GS All</b>
<b>8</b>	<p>Update – Paediatric nephrology Studies and Research SH – see slides</p> <p>RADAR, ECUSTEC and NEPHROS due to start</p> <p>Clinical Research Unit in UHW due to open to children this year to support research</p>	
<b>9</b>	Audit see above transition and DGH activity	
<b>10</b>	Radiology – carried over	
<b>11</b>	<p>Future Study day (Alexion sponsored) – suggested date and topics (AKI?)</p> <ul style="list-style-type: none"> <li>Topics HTN (Raj) Electrolyte abnormalities</li> </ul>	

	<ul style="list-style-type: none"> <li>• Would Alexion fund AKI speaker e.g. David Milford and another speaker (Tullus)</li> <li>• Trainee cases or audits please</li> <li>• Organ Donation and AN nephrology JvV will speak on</li> <li>• SH – research studies or Moin Saleem</li> </ul> <p>Try POWH in Early December (Welsh Paeds 10/11/17 so avoid that date)</p> <p><b>MJE to book venue, liaise with Alexion.</b></p> <p><b>SH to ask Dr Milford to talk.</b></p>	<p><b>MJE</b></p> <p><b>SH</b></p>
<b>12</b>	<p>Date and time and venue next meeting</p> <p><b><i>Friday December 1<sup>st</sup> 2017 9.30- 4.30 – with study day POWH booked.</i></b></p>	

Michelle James-Ellison 16.8.2017