



# British Association of Paediatric Nephrology Kidney Quality Improvement Partnership Quality Improvement Day

*Birmingham  
Friday 9<sup>th</sup> November 2018*

## Summary Report

## 1. Introduction

On 9<sup>th</sup> November 2018 over 100 members of the paediatric nephrology multi-disciplinary team - including doctors, surgeons, nurses, play-workers, dieticians, pharmacists and psychiatrists - came together in Birmingham to discuss and debate how to improve the quality of kidney care for children across the UK and Ireland. The programme was organised and led by members of the paediatric kidney community, and focussed on reflecting on current practices, looking at patient data and variation amongst renal units, and hearing about national projects currently taking place in the kidney community. You can view the [programme of the day here](#).



The day presented an opportunity to begin collaborating on quality improvement across units and professions, and to think about what priority area the paediatric renal network should focus quality improvement on over the next 12 months.

The three national topics that formed the focus of the meeting were:

- 🍷 Home therapies – Peritoneal dialysis and home haemodialysis
- 🍷 Vascular access – Central lines and AV fistulas
- 🍷 Transplant first

## 2. How KQIP can help our patients

### Principles of quality improvement



Dr. Amanda Newnham, Nephrologist from Leeds Children's Hospital, began the day with a presentation outlining the principles of quality improvement and sharing an example of a successful quality improvement project from her unit. The presentation set the scene of the day and was an excellent example of quality improvement methodology, including the importance of using the [NHS Change Model](#) when planning quality improvement, and communicating a clear shared purpose amongst all those involved before initiating change. [You can view the presentation from Dr Newnham here](#).

## Trios approach – group work and discussion

An interactive session led by Dr Daljit Hothi and Dr Caroline Anderson followed. Attendees were asked to discuss three questions,

1. What do we do well?
2. What are the major challenges facing our patients?
3. What stops us addressing those challenges together (barriers)?

Answers on post-it-notes were discussed before being grouped into key themes which are summarised below.

### A: What things do we do well?

#### **Family centred care (19 post-it responses)**

This theme included supporting families’ individual needs, supporting families to deliver care at home, parental/carer education, managing complex family needs and family and patient focussed care (putting their needs first). Forming focussed, tailored and strong relationships with families and patients was also mentioned.

*“Going the extra mile”*

#### **Patient centred care (21 post-it responses)**

This theme included individualised, holistic and flexible care, compassionate support for patients, supporting children step-by-step through treatment and involving patients in decisions about their care. People also mentioned the ability to fit illness into every-day life (life/school/trips), psychosocial support for patients, and sharing information about the needs of patients and their families.

#### **Multi-disciplinary team-work (44 post-it responses)**

The strongest theme that came out of these discussions was the strength of the multi-disciplinary team approach, and the hard-working, open and positive staff that make up the paediatric kidney work-force. Other elements within this theme included experience, leadership, collective thinking, collaborative networking and good communication between professions, clinics, units and across the network.

### B: What are the challenges facing our patients?

#### **Infrastructure (18 post-it responses)**

This theme included staff shortages, lack of community based support or outreach, silo working, increased demands, budgets and a lack of haemodialysis capacity. Access to home haemodialysis equipment, theatre space, and new prescriptions, for example home haemodialysis drugs, were also mentioned as key challenges.

**Geography (18 post-it responses)**

Distance to treatment, travel and transport were all repeatedly mentioned as challenges facing children with kidney disease. Variation of treatment by location was also noted as a challenge as well as the variation in funding available in different areas.

**Social and psychosocial challenges (31 post-it responses)**

Socio-economic status, financial issues for families, lack of psychosocial support, and the impact on family life and other family members were all mentioned. This theme also included cultural differences, the uncertainty of the transition to adult services, adolescence, long stays away from home and a disrupted education / impact on employment.

*“Dealing with the burden of kidney disease and maintaining a ‘normal’ family life”*

**C: What are the barriers to improvement?**

**Resources (45 post-it responses)**

This extremely strong theme included staff numbers and skill mix, funding, time and workload as barriers to improvement. The complexity of management, variance in practice, lack of training and lack of dialysis machines, beds and space were other barriers mentioned under this theme.

*“Parental and child expectations being managed within current resources”*

**Differing priorities and competing demands (7 post-it responses)**

The competing demand of different stakeholders (disciplines, families and patients) was seen as a barrier, as well as different priorities (health versus life), variances in culture, and differing perspectives of members of staff were all seen as barriers to improvement.

*“Not thinking outside the box”*

**Communication (12 post-it responses)**

- Communication with patients – this included fully understanding patient needs, time to build trust/overcome fear, a lack of age appropriate information and differing backgrounds.
- Communication between units and the network – this included recording and sharing data, guidelines, and the lack of contact with other units.

This interactive session enabled delegates to begin reflecting on their current practices, and what challenges, successes and barriers they have come across when delivering care. These themes will all affect quality improvement work in the future and a good understanding of the reality of care delivery on the ground is an important starting place for any change initiative.

### 3. Home therapies

The first of the topic areas discussed was access to home therapies, covering both home haemodialysis and peritoneal dialysis.

To find out more about the Home Therapies programme, you can visit the [KQuIP website](#) or read a blog written by Dr Richard Fluck (national project lead for the Home Therapies programme DAYLife) on the Think Kidneys website [here](#).

The session began with Dr Daljit Hothi and Dr Amanda Newnham presenting an overview of the home therapies data that a number of the organising committee had collected from the 13 paediatric kidney units in preparation for the day. The data was presented in two parts:

- The numbers of patients on haemodialysis, peritoneal dialysis and home haemodialysis, along with results from a survey on units' home haemodialysis programmes
- A presentation detailing peritonitis cases, peritonitis rates and PD exit site infection cases

[View the data presentation on home therapies here.](#)

Following on from this data, Dr Richard Fluck presented on the DAYLife national project. The presentation focussed on the variation of access to home therapies between renal units nationally and over time, the importance of shared decision making in access to treatment options, the DayLife project structure, measurement, aims, as well as the support available for units taking on this work.

[View the presentation on the DayLife project here.](#)

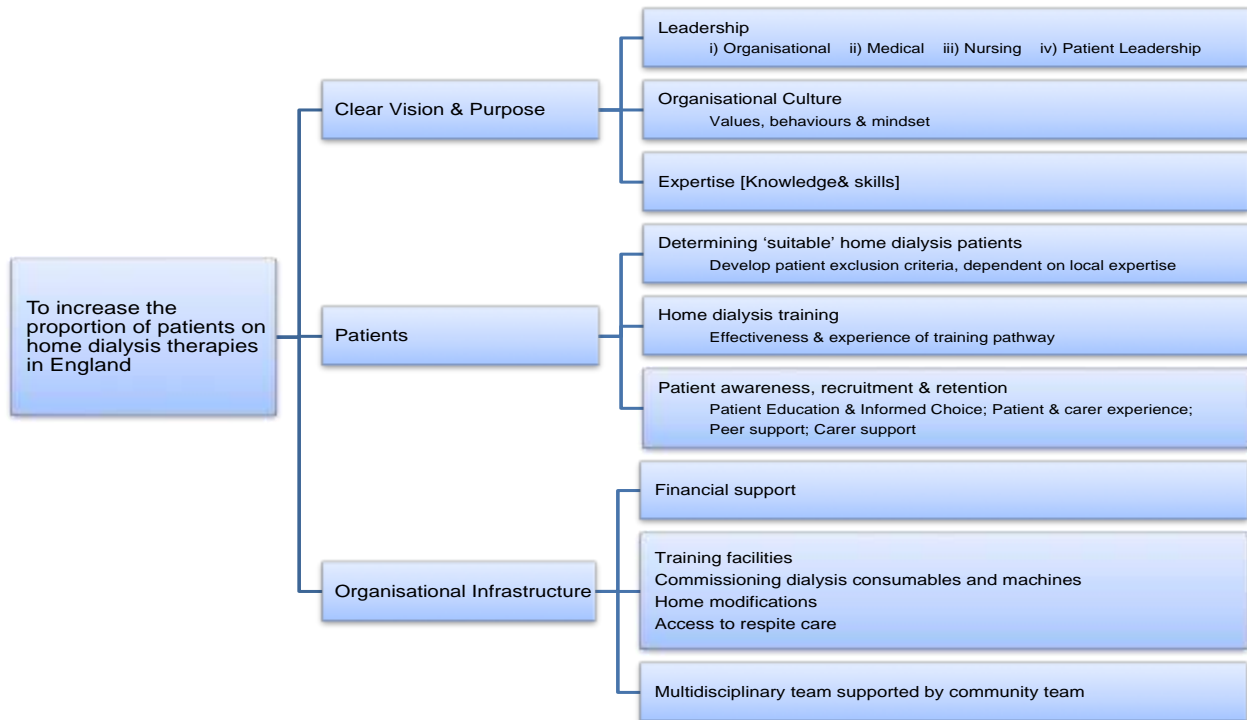
#### Group work



Facilitated by Dr Richard Fluck and Dr Daljit Hothi, delegates were asked to review a driver diagram for the DAYLife project in their teams (see below), and plan a simple Plan-Do-Study-Act cycle addressing one of the drivers on the far right hand column.

Ideas were then fed-back and discussed in an open forum discussion.

## DRIVER DIAGRAM: Home Dialysis



### Aims for improvement included:

- **Determine suitable home dialysis patients**  
*Developing exclusion criteria, patient choice and housing suitability through early home visits*
- **Create the organisational infrastructure to introduce home dialysis**  
*Create a business plan by auditing current services, identifying commissioning services in place, cost benefit analysis and assessing viability*
- **Improve the time from decision made for home dialysis, to having home dialysis**  
*Engage with commissioners to provide more home dialysis trainers and resources*
- **Improve organisational culture**  
*Increase awareness of home therapies within own teams – survey workforce on awareness and tailor education to fill gaps. Agree shared vision for service development*
- **Improve experience of patients on home therapies in UK and Ireland to increase patient awareness, recruitment and retention**  
*Identify suitable measures/adapt adult measures to paediatric setting, send out questionnaires, identify common themes to plan improvement*

**🍌 Improve patient awareness, staff recruitment/ retention, carer support skills, resources and respite community support**

*Identify workforce to provide training to others on early involvement and shared decision making. Evaluate the difference by measuring numbers. Use tech for problem solving - communication, social media, WhatsApp, change to unintended admissions?*

#### 4. BAPN Access complication audit

Dr Vincent Tse, consultant paediatric nephrologist at Newcastle gave a short presentation on the BAPN access complication pilot audit that was carried out in 2016. This was a great example of how data can be used to assess a unit's performance against other units and learn from others. [You can view the presentation and data here.](#)

#### 5. Transplantation

This session opened with three short presentations around the theme of transplantation, giving attendees some background into work that has already been done, the data available on access to transplantation in paediatric nephrology, as well as the Transplant First programme, supported by KQuIP.

Dr Stephen Marks gave a presentation outlining the **Access to Transplantation and Transplant Outcome Measures In Children (ATTOMIC) Study**. [You can view the presentation here.](#)

Dr Jan Dudley then gave an overview of a [project proposal to standardise immunosuppression regimens for UK paediatric renal transplantation.](#)

Mr Ron Cullen closed the presentations with a brief overview of the Transplant First programme. This is the programme the paediatric network could take on with KQuIP's support. [You can view the Transplant First presentation here.](#)

There are further resources and information on the [Transplant First programme on the Think Kidneys website here.](#)

A facilitated group discussion was then had in two parts:

1. What are the barriers to pre-emptive transplant listing / living donation in your unit / across the network?
2. A) What have you introduced that has worked well / you are proud of?  
B) What do you need to make improvements in patient pathways?  
C) What can you commit to now?

Below is a short summary of the discussion:



What are the barriers to accessing transplantation?	What has been introduced that has worked well?	What could we do to improve access to transplantation?
<p><b>Health of patient</b></p> <p>Size Current suitability of recipient Co-morbidities Compliance 'Crash-landers' Malignancy Infants born in ESRF</p> <p><b>Differing clinician views</b></p> <p>Differing views on patient size/BMI/weight Process is not standardised Transplant coordinator taking a long time to make decisions Team awareness</p> <p><b>Theatre time</b></p> <p>Access to paediatric surgeons Ward staffing levels / resources Surgical procedures prior to transplantation</p> <p><b>Communication between teams</b> (e.g. urology)</p> <p><b>Family engagement</b></p> <p>Parent expectations 'Persuading' potential donors Informed consent from parents Burden for carers to donate Psychosocial support for LRD Social and cultural factors Beliefs Mental health Safeguarding Lack of family members willing</p>	<p><b>MDT monthly meetings</b></p> <p>MDT involved in work-up Joint speciality Bi-monthly transplant meetings Well informed, experienced MDT Transplant coordinator role Clear roles and responsibilities</p> <p><b>Work-up plans</b></p> <p>Completed and accessible when deceased donor is offered Good transplant pathway Early discussions about treatment options Education programme</p> <p><b>InfoKid</b></p> <p>Shared across the country (<a href="#">for more information click here</a>)</p> <p><b>Strong links between centres</b></p> <p>Liaison with adult centres</p> <p><b>Psychosocial input</b></p>	<p><b>Communication</b></p> <p>IT improvement Patient held/electronic transplant document Public awareness of donating kidneys Use social media to increase donor pool</p> <p><b>Standardisation</b></p> <p>Time to work-up should be standardised Pathway/timeline agreements Standardise guidelines around weight /height for transplant Facilitator for differing opinions Independent review of access – standardised pathways Improving psychosocial support for all at a set point in transplant journey Set goals for compliance which are measurable Consistent approach to listing patients Study each centres pre-transplant pathway</p> <p><b>More theatre slots</b></p> <p><b>Educating staff</b></p> <p>Education on all transplant options - LRD/DD/paired Transplant link nurse role Earlier identification of patients Involving other teams with complex cases Urologists to attend MDT meetings with the renal team</p>



<p>to donate Donor suitability</p> <ul style="list-style-type: none"> <li>• <b>Geography / reluctance to travel</b></li> <li>• <b>Length of time for LRD work-up</b></li> </ul>		<p>Include all MDT members in meetings Reflections – reflect on cases Collaborative work between centres</p> <ul style="list-style-type: none"> <li>• <b>Parental expectations, management and involvement</b></li> </ul> <p>Patient feedback of process Get patient and family feedback Are we explicit enough about risks of dialysis? Peer support</p>
<p style="text-align: center;"><b>What can we commit to now?</b></p> <ul style="list-style-type: none"> <li>• Better communication</li> <li>• Audit</li> <li>• Patient feedback</li> <li>• KQuIP</li> </ul>		

## 6. Vascular Access

The final area of quality improvement that was discussed was Vascular Access.

The quality improvement programme that KQuIP supports, focussing on improving vascular access, is **MAGIC (Managing Access by Generating Improvements in Cannulation)**.

The aim of the MAGIC programme is to:

- Improve rates of AVF and AVG use through preserving the lifespan of existing AVF and AVG
- Improve patient experience of needling, to encourage patients to choose AVF or AVG as their preferred type of Vascular Access
- Promote future quality improvement in Vascular Access

You can read more information on the [MAGIC programme on the Think Kidneys website here](#).

A multi-professional team from both the national MAGIC programme board and the paediatric network have been working on adapting MAGIC to the paediatric setting over the past few months, as well as gathering unit level data from centres across the UK. The session began with an

introduction to Vascular Access by Mr Francis Calder, and then a number of those involved in paediatric MAGIC work then presented on this programme. The presentations can be viewed by clicking on the links below:

- [HD line access protocols – Jean Barrett](#)
- [Vascular Access survey data – Francis Calder](#)
- [Introduction to MAGIC – Katie Fielding and Lynsey Stronach](#)

Group discussions were then held on tables around the following questions:

1. What do you think is strong / good about your vascular access care for haemodialysis?
2. What barriers do you have to using AV access for haemodialysis?
3. Do you feel you use AV access enough to feel competent / confident in their management?  
What would increase your confidence?

The below table summarises the main discussion points from the group-work:

<p><b>What do you think is strong / good about your vascular access care for haemodialysis?</b></p>	<p><b>What barriers do you have to using AV access for haemodialysis?</b></p>	<p><b>Do you feel you use AV access enough to feel competent / confident in their management?</b></p> <p><b>- What would increase your confidence?</b></p>
<p> <b>Guidelines</b></p> <p>Standards/ national guidance Excellent practice, policies and protocols Protocol for exit site management Competencies</p> <p> <b>Skilled staff</b></p> <p>Staff willing to learn Confidence Enthusiasm vocally Training in managing CVL and knowledge Resources (lead nurse/ surgeon/ play specialist) Highly skilled nurses</p>	<p> <b>Training</b></p> <p>Educational level Understanding and cooperation General education of rest of hospital Critical mass of skilled nurses Lack of training to access or care for Lack of confidence with staff Lack of experience with staff Staff rotation</p> <p> <b>No clear pathway on fistula</b></p> <p>Getting theatre slots Waiting time for surgeon that can do fistula Consistent approach – TX</p>	<p> <b>Standardised AVF access training</b></p> <p>HD education and protocols</p> <p> <b>Experienced unit leads and educational resources</b></p> <p>Pro/ gold standard Vascular access surgeon and consultant Access to practical experience in adults Enthusiastic nursing staff (ed) leadership and aspiring young nephrologists Access in a timely manner to surgical expertise particularly if not in same site</p>

<p>Vascular surgical experience Interventional radiologist Play specialists Psychologist and play support Nurse educator Self-cannulation carer</p> <p><b>Good links with adult services and support</b></p> <p>Excellent adult programmes for an access on-site</p> <p><b>Designated AVF clinics</b></p> <p><b>Vein preservation</b></p> <p>Hospital wide awareness re: 'lifeline'</p> <p><b>Low CVL infection rates</b></p>	<p>surgeon clinic Getting appointment in clinic</p> <p><b>Unit culture</b> Acceptability Not promoted enough Unknown – how long until transplant Time invested in getting transplant first rather than thinking of the future</p> <p><b>Patient/ family perception</b> Pt/ family (reluctance) Body image Patient perceptions Family beliefs – fear Needle-phobia Fistula – 'scary word' 'hideous' change of attitude and culture Psychological aspects Low numbers of patients Confidence – currently only 1 patient self-needling</p> <p><b>Risk</b> Risk of clot of fistula during transplant Not always 1st time successful with fistula Failure rates Infection rates</p>	<p>Local nurse educating skills Resource to support KQuIP program participation</p> <p><b>Parent and patient confidence</b> Self-needling and buttonhole formation</p>
---	--	--

---

## 7. Quality improvement in practice

Professor Paul Cockwell and Dr Daljit Hothi led the final session of the day, bringing together the debates and information that had been discussed.

The key points that were emphasised to the network by Professor Paul Cockwell, KQuIP Co-Chair, were:

- The paediatric renal community are in a unique situation. Whilst the **network does not currently have the same statutory requirements as adult renal**, for example the [Getting in Right First Time](#) initiative, this is likely to be implemented in the next three to five years. **KQuIP provides a unique opportunity to prepare for these requirements**, to develop the **skills** needed within your teams to carry out quality improvement initiatives, to build a **collaborative network** of professionals with key quality improvement skills, and to **share learning** with each other **ahead of the curve**.
- **Data is vital** in quality improvement. The paediatric network needs to work out **what the measurable standards** they are going to prioritise are. The UK Renal Registry can help with this. KQuIP can also provide **real-time data tools** to support quality improvement work.
- Your units need to clearly define the **leadership for KQuIP**. Units should identify a minimum of two QI leads to drive the KQuIP project locally and share their QI activity across the Paediatric KQuIP network – this should be at least one **clinical nephrology and one multi-professional team member**. It would be fantastic for **patients/carers** to be involved and we would welcome named patient/carer QI leads as well.
- **Your service must buy into KQuIP for it to be successful**. KQuIP can support in training, project management, measurement, and arranging collaborative meetings, however the service leads will need to allow the quality improvement leads to have the **space and the time to deliver** the programmes and attend the training days.

It was agreed that units would prioritise identifying QI leads initially, before opening up discussions with the wider teams locally and deciding on a quality improvement priority area they would like to focus on as a unit. This will be fed-back to the KQuIP Paediatric team and plans will be made regarding how best to deliver each programme within the KQuIP structure once the project priorities are finalised.

## 8. What next?

No conclusive priority from the topics presented was decided by every unit on the day, so there is still some work to do before the network can get started with KQuIP. We want to keep the motivation and drive from the day going, so these are a few next steps for units to focus on over the next two months, to ensure we can get started as soon as possible.

---

### **Quality Improvement (QI) Leads – to be identified by the end of November (30<sup>th</sup> November 2018)**

Units should identify a minimum of two QI leads to drive the KQuIP project locally and share their QI activity across the Paediatric KQuIP network – this should be at least one clinical nephrology and one multi-professional team member. It would be fantastic for patients/carers to be involved and we would welcome named patient/carer QI leads as well. **Please email the names of your QI leads to the KQuIP team (contacts found at the end of this report).**

### **QI leads to gain approval from Clinical Directors for KQuIP commitment (2 day leadership course + 4 days training over one year as well as space to plan and deliver the QI project locally with KQuIP support)**

The QI leads identified will be offered training in leadership, QI and measurement from KQuIP. It is hoped the leads will form a team of QI champions in the network that can take collaborative projects forward into the future. The training days will be an opportunity to build relationships as well as learn and take back important skills to your role.

### **Quality Improvement leads to decide, with their wider teams and patients, their *KQuIP priority project/s* – by the end of the year (31<sup>st</sup> December 2018)**

Once the QI leads have been identified, a wider discussion with local teams is needed to discuss what project your team would like to prioritise. If your unit would like any support calls or visits between now and 18<sup>th</sup> January from the KQuIP team to help guide these discussions, please do get in touch with either [Catherine Stannard](#) or [Rachel Gair](#) by email who are supporting the KQuIP paediatric QI work.

### **KQuIP Paediatric priorities to be signed off at the BAPN AGM – 18<sup>th</sup> January 2019**

The BAPN AGM which is being held on 17-18<sup>th</sup> January 2019 will be an excellent opportunity to finalise the KQuIP projects the paediatric kidney community will be taking on over the next year, and to launch the QI priorities for 2019. There will be a session on the agenda dedicated to this and so we ask all units to have a clear priority project identified to bring to this meeting.

## **9. Posters**

Thank you to all who brought their fantastic Quality Improvement posters to the event. There is evidently so much activity going on already around quality improvement within the network and we hope KQuIP can build and grow this already great body of work. The posters will be available to view on the KQuIP website shortly.

## 10. Acknowledgements

### Sponsorship

With thanks to our sponsors who made the BAPN/KQuIP Paediatric Day possible through the purchase of exhibition stand space:



And to Kidney Care UK for kindly funding KQuIP programme management.



### Speakers

A huge thank you to everyone who contributed to the day, whether through chairing a session, giving a presentation or facilitating discussions. All contributions were of an excellent standard.

### Delegates

Finally, thank you to everyone who took the time to attend the event and for making the day so energetic and positive.

## 11. Contacts

To find out more about the Kidney Quality Improvement Partnership, or to ask any questions please contact:

### KQuIP Programme Managers – Paediatric

Rachel Gair

[Rachel.gair@renalregistry.nhs.uk](mailto:Rachel.gair@renalregistry.nhs.uk)

Catherine Stannard

[Catherine.stannard@renalregistry.nhs.uk](mailto:Catherine.stannard@renalregistry.nhs.uk)

### KQuIP Paediatric Lead

Daljit Hothi

[Daljit.Hothi@gosh.nhs.uk](mailto:Daljit.Hothi@gosh.nhs.uk)