

Scottish Paediatric Renal and Urology Network (SPRUN)

Annual Report 2023/24

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Introduction

The Scottish Paediatric Renal and Urology Network (SPRUN) is a nationally designated managed clinical network, established in 2004. The network encompasses renal and urological disease in children and young people up to 16 years old, who may require specialist intervention but who can also be managed locally. Specialist care is also offered to young people aged 16-18 years, who are being prepared for transition or by an individual case by case basis. The Network facilitates the care of children and young people with renal disease via local teams delivering care close to home with information and intervention being provided, as necessary, by the specialist unit.

Tertiary paediatric nephrology services are based at the Royal Hospital for Children (RHC) in Glasgow, which also hosts national services such as the renal transplant service, acute and chronic dialysis service, as well as managing children and young people with severe acute kidney injury, complex nephro-urology and rare diseases such as tubulopathies. The paediatric transplant and dialysis services are nationally designated with the aim of reviewing the more complex and rare renal conditions to be included in a wider paediatric renal service designation.

Each local renal service comprises a paediatrician with an interest in nephrology, as well as nursing and wider multidisciplinary support. The local teams are supported by a visiting paediatric nephrologist from the tertiary centre who attends regular joint clinics. Some renal patients are managed locally out with the combined renal clinics.

Tertiary paediatric urology services are provided by three multidisciplinary teams in Scotland: Aberdeen, Edinburgh and Glasgow. They include Paediatric Urologists and Urology Specialist Nurses at each tertiary centre. The Paediatric Urology teams in Scotland work closely together and hold regular “bladder meetings” to discuss cases. All three centres provide outreach to local centres with satellite clinics and close communication to support the care of patients locally as much as possible.

Current position

In total SPRUN achieved 21 of 26 (81%) of it's agreed objectives in 2023/2024. Significant progress was with the networks data plan and various other projects such as transition and education.

Updates on the projects which were not completed;

- **Continue to develop refreshed SPRUN vision** – this paper has been drafted and is awaiting feedback
- **Audit the uptake and impact of NS guideline, develop action plan if appropriate** – significant progress has been made with this objective. An audit is taking place at a local centre which is taking longer than anticipated
- **Baseline audit standards of care for paediatric renal and develop an action plan** – standards of care are signed off however the audit has not taken place yet due to capacity issues.

- **Produce a bi-annual newsletter** – only one newsletter was circulated, this was mainly due to resource issues within NSD
- **Lead clinician recruitment / extension** – while this was signed off by the SPRUN SG there is currently a hold on extensions within NSD

Lead Clinician update

We have had a busy year in SPRUN and continue to progress our many objectives focusing on supporting the delivery of renal as well as urological care to children and young people throughout Scotland.

The education programme remains a key aspect of our work, with professionals across disciplines and health boards attending. Face to face meetings have now been incorporated allowing networking with individuals and we hope to incorporate further such meetings in the coming year.

The Peritoneal Dialysis (PD) Data review is almost complete and will soon be published, highlighting well issues that should be addressed to continue to provide good, quality care to our PD patients in Scotland. The transplant work-up data project is now ready to be implemented and with it we look forward to improving logistics and communication of transplant work-up throughout the network.

Additional small projects that have been completed include revision of Joint Clinic Guidance as well as an initial report on transition. As with many projects, additional or new lines of work are created and we are aiming to widen the transition work in the future. And so we look forward to another year to progress the objectives of SPRUN including publication of the PD project, widening of transition work, ongoing education sessions and many others. Once again my gratitude for the time and input of the Steering Group, those individuals working within the specific projects in SPRUN, contributors to the education sessions and indeed all those involved with SPRUN over the past year.

Highlights

Education

SPRUN education sessions provide general paediatric teams across Scotland with tailored CPD education for renal and urology conditions. The programme is a rolling 3-year programme which covers the renal and urology curriculum. Without these sessions there would be no dedicated renal and urology education for local DGH teams seeing renal and urology patients in their general clinics. These education sessions are tailored to each condition but in the main they cover:

- The basic principles of managing common renal and urology conditions – ensuring that patients care is as close to home as possible
- The management of more complex renal and urology conditions and when to escalate these patients to paediatric renal and/or urology
- Case studies, investigations and common findings

Sessions are delivered each month, with a break in Summer and Winter, via Microsoft teams to ensure equity of access. Two sessions this year were also open to face-to-face attendance to allow for networking, these sessions are however still available to

access via Teams. Following each meeting, a recording of the session is made available on the education Teams channel.

Six sessions have taken place in 2023/2024. More information on these sessions is included below:

Date	Title	Attendees	Number of boards represented
28/04/23	Cystic Renal Disease Teaching Session	14	10
30/05/23	Joint Renal/Rheumatology Study Day	49	11
29/08/23	CAKUT/Radiology Teaching Session	18	9
31/10/23	Transition Teaching Session	33	6
30/11/23	Dialysis Study Day	19	8
29/02/24	Ante/Postnatal Renal Anomalies Management & Guideline	31	8

All sessions now use a standard survey to evaluate them. A summary and feedback from 2023/24 sessions are below:

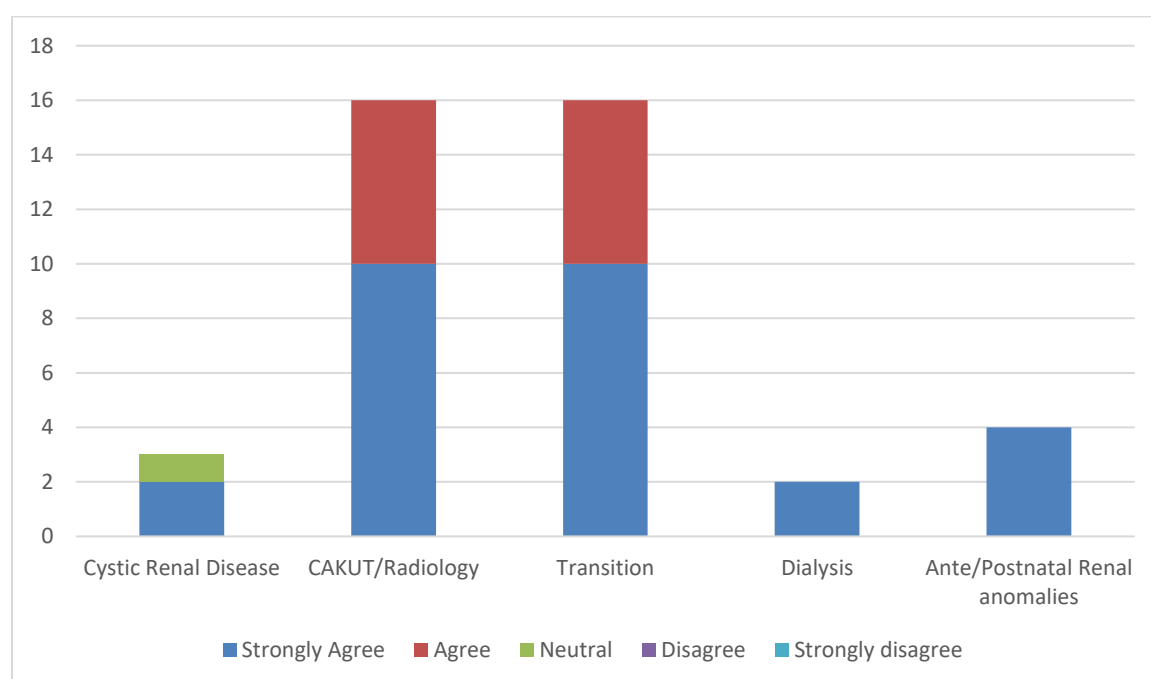


Figure 1 – Was the event objective met? All events 2023/2024

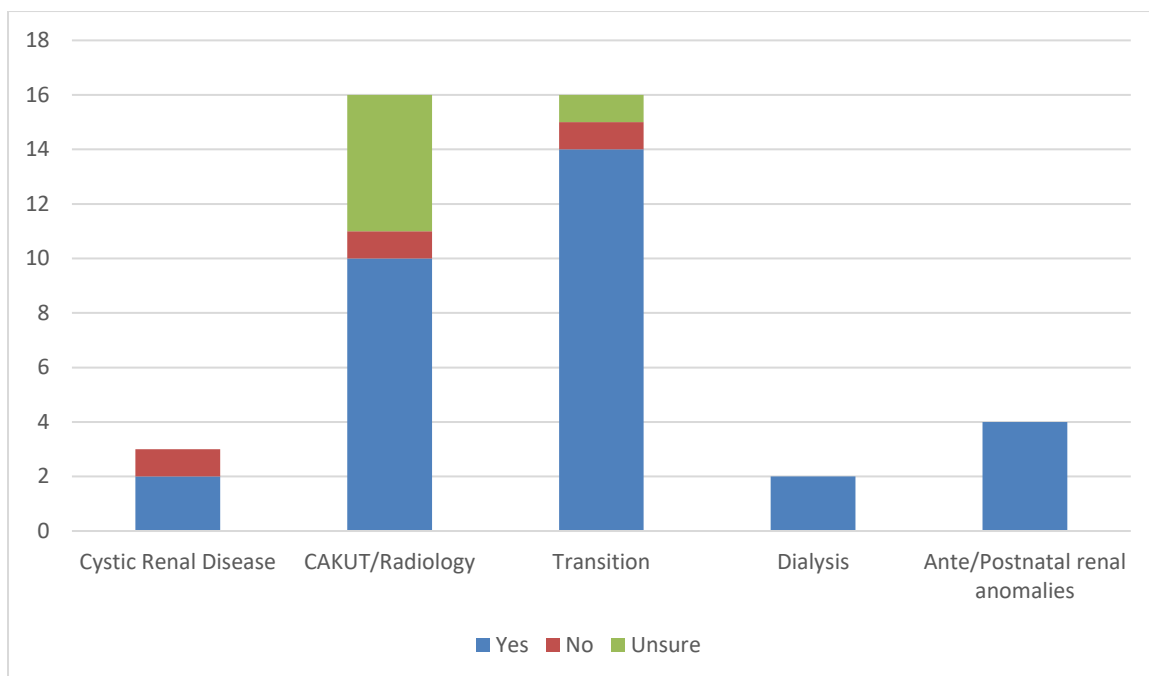


Figure 2 – Was your practice influenced / consolidated

Figures 1 and 2 above show two of the standard questions included in evaluations. Did the event serve its purpose and is practice influenced / consolidated. These questions show that the SPRUN events continue to meet the needs of stakeholders. These responses were utilised for the development on the new education strategy that has been developed.

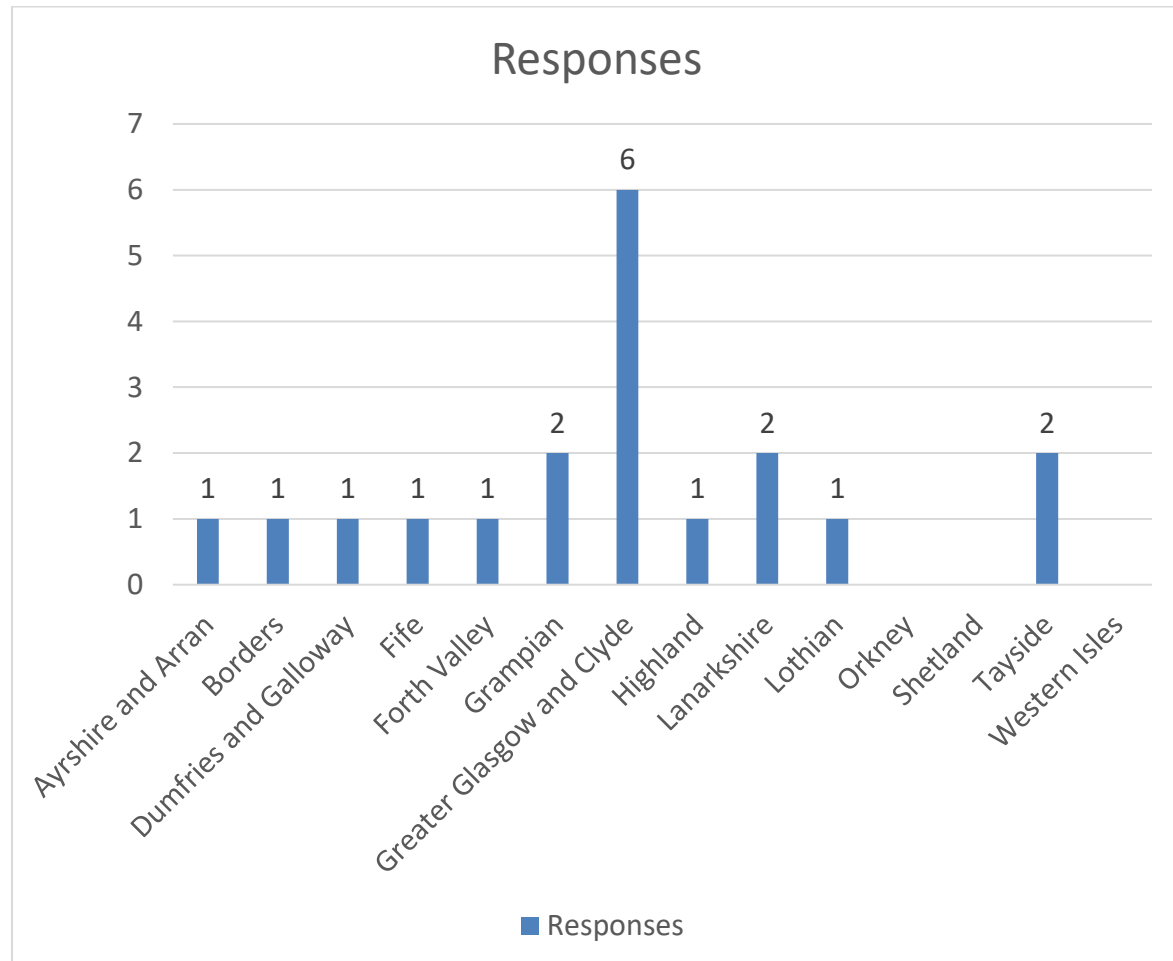
Some specific feedback received from attendees is below:

- *“Reference to the various consensus statements / guidelines highlighted to try and ensure more consistent follow up / surveillance of patients with some of the cystic kidney diseases covered.”*
- *“Learnt so much about anatomy and anomalies of renal tract/bladders and case presentations very interesting”*
- *“It consolidated understanding of CAKUT and feel more confident approaching it now.”*
- *“Extremely interesting talks all the speakers, looking forward for attending more sessions like these.”*
- *“....a cystic fibrosis nurse....attended today to find out about transition process used and hopefully to implement this into local service.”*
- *“Keen to see if can get a support worker or peer group set up locally. Better familiarity with Ready steady go.”*
- *“....general paediatrician so it was a very informative event....”*
- *“Especially the advice I would give to my patients with renal disorder would be guided by this, e.g. dietary and treatment modalities.”*
- *“It will help in managing neonatal kidney problems referred by FM.”*
- *“A clear up to date guideline regarding both antenatal & post natal anomalies, with what to do, where & when.”*
- *“Not sure practice will change immediately, but certainly gives assurance that what we are doing is in line with everywhere else.”*

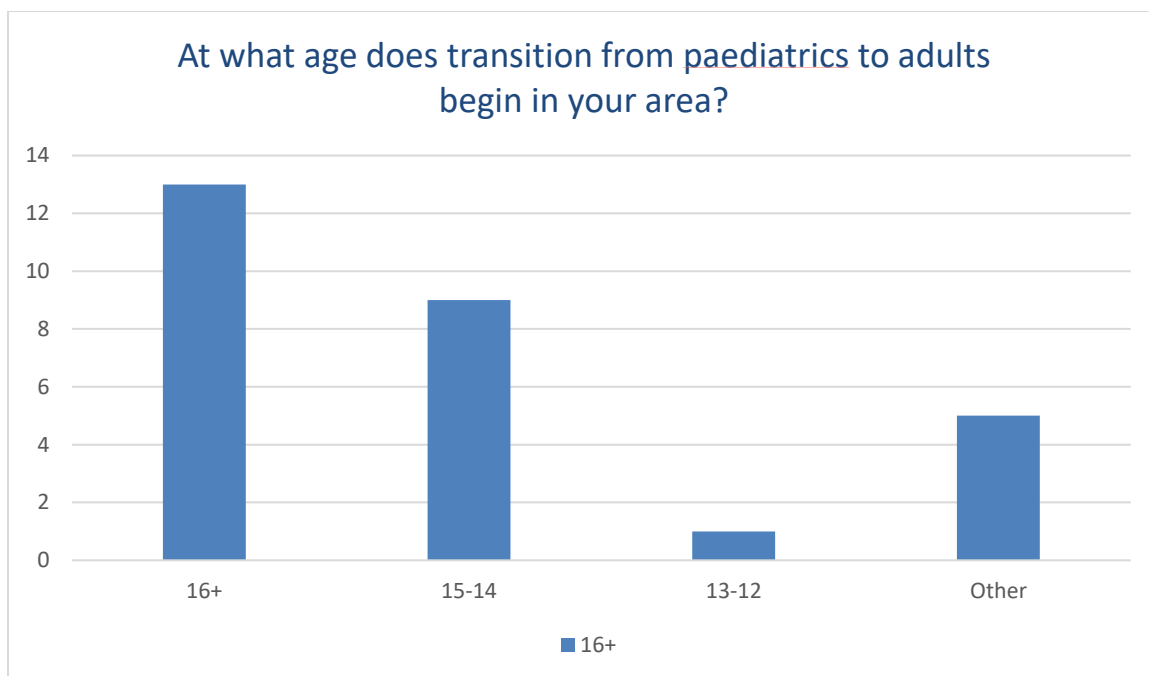
Transition

SPRUN participated in the NN review of transition arrangements. The objective of this project was to review current arrangements with a view to agreeing and delivering an action plan following feedback from local teams and patients. Current arrangements were reviewed via a MS form circulated to local renal teams.

A summary of the data received is below;

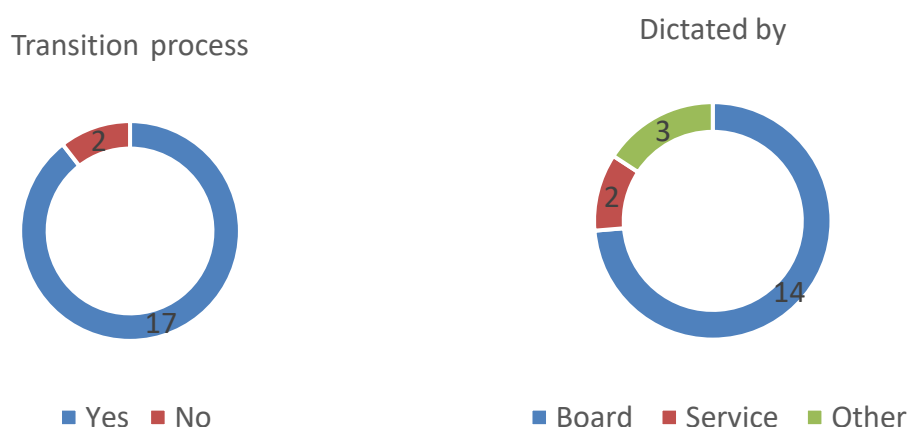


In total there were 19 responses received with engagement from across the country, at least one response was received from every mainland board. Responses received were also a good split of Nephrology (3), Local Link Paediatricians (11) and Nursing (5).

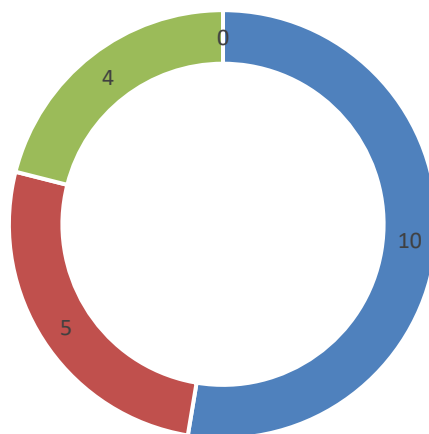


The data above identified that there was some variation in the age at which transition begins. The “other” responses included no set age and earlier than 12.

The survey then went onto look at local transition arrangements. With services being asked to confirm if their service had a local transition process and who decided the age of transition. 17 responses confirmed that there was a local transition process in place with the majority, 14, advising that their board dictated the age at which patients transition.



Services were asked if they held dedicated transition clinics and if so, what that looked like. 15 of the 19 responses confirmed that a dedicated transition clinic was in place, although only 5 of those clinics were multi-speciality clinics.



■ Yes - individual per service ■ Yes - multi specialty ■ No dedicated transition clinic ■ Other

Following review of the data, some next steps have been agreed. They are:

- Survey to Urology
- Survey to adult services to understand process from adult perspective
- Set up a SLWG to develop an action plan

Data

Peritoneal Dialysis (PD)

Peritoneal dialysis is an option for patients with end stage renal failure (ESRF). It is a preferred option in younger children with ESRF, older children/young people (CYP) who can then continue to attend daytime education. As it is undertaken in the home with parental supervision, it is logistically a preferred option for many, who live a distance from the renal centre in Glasgow. It is however a specialised treatment, requiring specialised training, sufficient nursing support (from a nurse with appropriate training) for parental education as well as professionals in nearby localities.

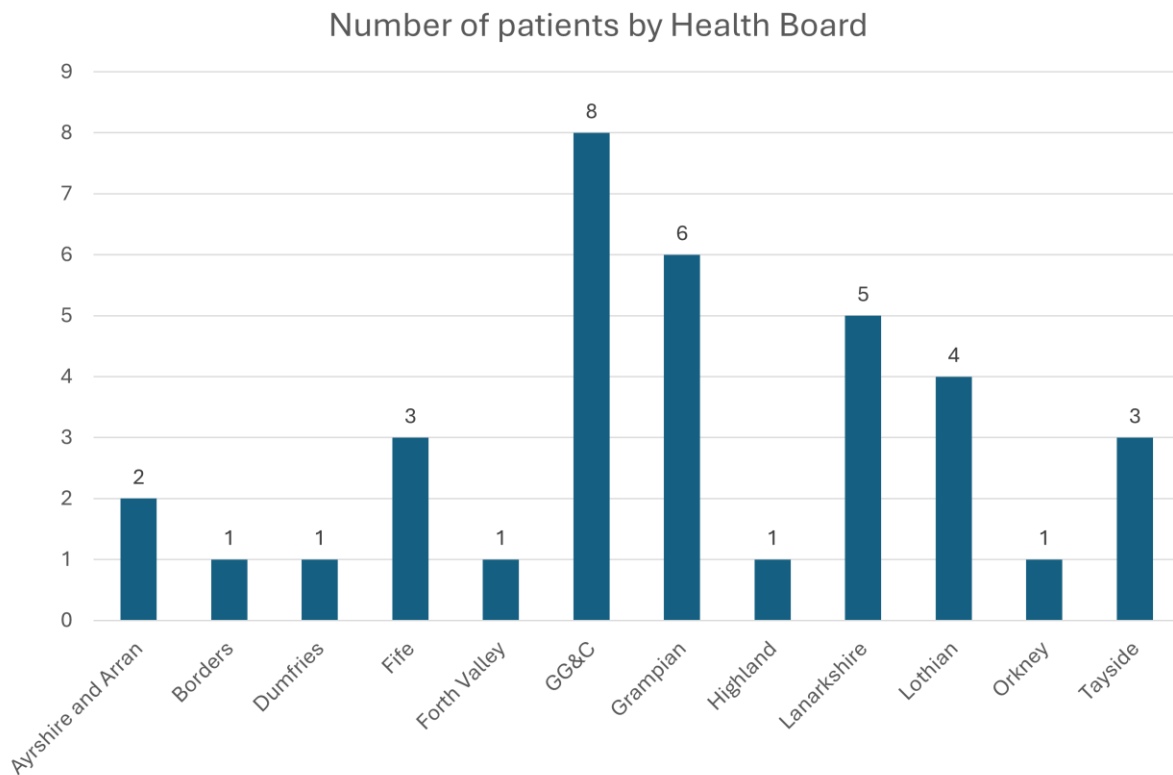
The PD service in CYP in Scotland is undertaken and supported primarily by the PD nurse specialist and the renal team based at the Royal Hospital for Children, Glasgow. Due to the specialised requirements of the service, for it to function currently and provide quality care to CYP, families need ongoing and frequent attendance at RHC, Glasgow. There is only one dedicated PD nurse in Scotland, based in RHC Glasgow.

The overall objective of the project was to scope the current PD service in Scotland to understand current processes and identify any areas for improvement. This was done in a number of ways:

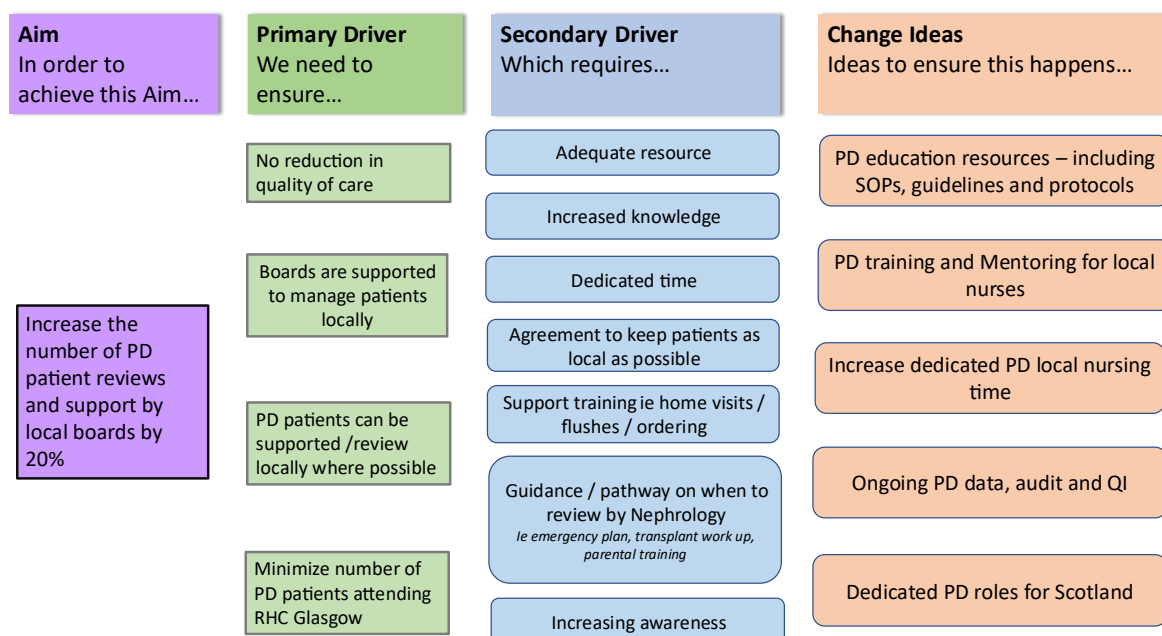
1. agreeing a data set which the PD service completed for each patient on PD since 2014. (2014 was chosen as a new PD machine was introduced at this time)
2. develop an action plan or best practice guidance – by reviewing and utilising the data collected and discussing alongside PD service staff

3. seeking patient feedback on the current service
4. work alongside other key stakeholders to understand how to implement any actions

In total there had been 34 PD patients in Scotland since 2014. A breakdown by board area is included below:



A full PD report is about to be published and includes analysis of all the data collected. Following this review and discussions with the local service, a PD Driver diagram has been developed to allow for small tests of change to the process and for this to be taken forward using QI methodology. In addition to this, PD will continue to be collected on an ongoing basis by the PD nurse specialist to allow comparison.



A second data set for transplant data has been developed alongside IMS. This data set will allow local teams and the Glasgow Renal team to review transplant workup to understand the current processes and identify any areas for improvement. This data set is now live with some local teams actively contributing to the project.

Stakeholder survey

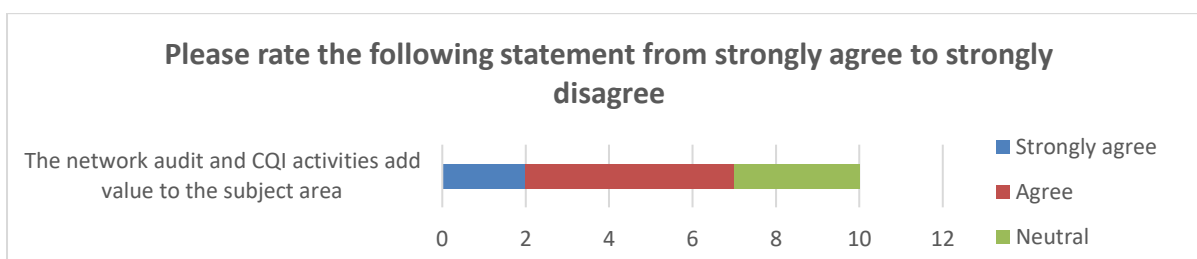
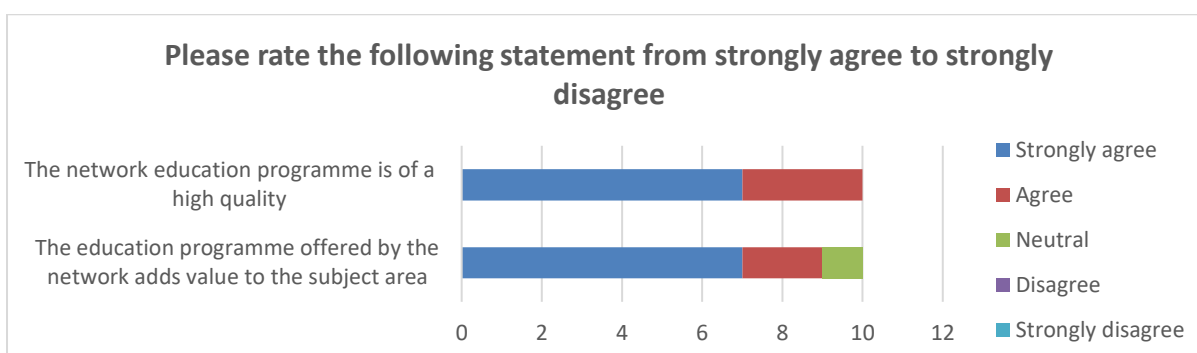
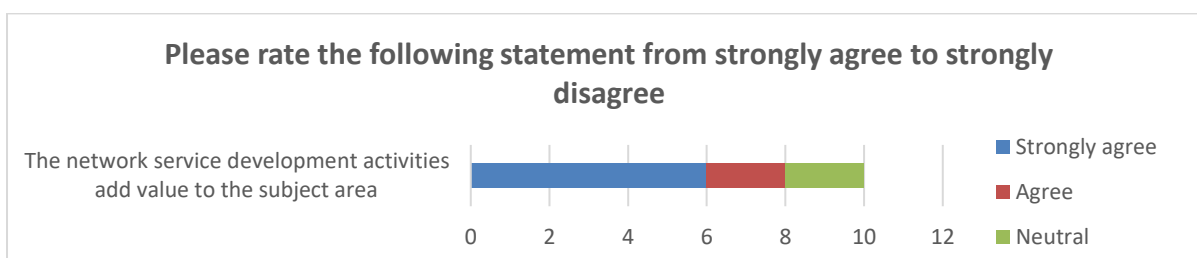
In order to seek feedback from stakeholders a National Network Survey was developed on MS Forms and open for responses from 18-29 March 2024. The survey was issued to all those stakeholders deemed to be actively participating in the network. Active participants ranged from Steering Group members to those who occasionally attend education events.

This table includes a summary of all survey responses. However, it is acknowledged that some response views may not be relevant to the role and or remit of the National Managed Clinical Network.

Strengths	Areas for Improvement
<ul style="list-style-type: none"> Very supportive. Team working; education; communication. Cross groups sharing of experience and expert level support. 	<ul style="list-style-type: none"> Improve communication and minimise jargon. Online transplant work-up grid.
Suggested Future Priorities (3-5 years)	Network Challenges/Threats
<ul style="list-style-type: none"> Continue to support professionals and patients - to provide best quality care in an equitable way through network. 	<ul style="list-style-type: none"> Senior members of NSD/boards not recognising/valuing network and its role.

<ul style="list-style-type: none"> • Ensure education events maintained; • Support documents - such as guidelines; information leaflets. • Audit and review on national level" • Ongoing provision of high quality education. Moves to expand the place of the electronic patient record SERPR into trusts throughout Scotland. 	<ul style="list-style-type: none"> • Complacency and lack of engagement, not that I see this at the moment. •
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A snapshot of the further responses is below:



Looking forward – 2024/25

Looking forward to 2024/25 the plans for SPRUN include:

- Deliver improvements in PD care
- Develop and deliver a transition action plan based on transition audits which took place in 2023/24
- Audit compliance against refreshed joint clinic guidance and identify action plan to address any gaps identified
- Continue with data plan

Finance

The finance spend for 2023/2024 is:

Education event and SG meeting (April 23) -	£1126.80
Printing of patient resources -	£ 206.00
Courier fees -	£ 52.38
Education event and SG (November 23)	£ 216.00
Total spend -	£1601.18

Risks and issues