

Scottish Paediatric Renal and Urology Network (SPRUN)

Annual Report 2022/23

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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. 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.

Paediatric renal and urology services provide care to children and young people (usually up to 16 years of age) from across Scotland who have kidney and bladder/urinary tract related health issues that require specialist input.

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 nephron-urology and rare diseases such as tubulopathies. Only the paediatric transplant service is nationally designated although this designation is currently being reviewed.

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 12/13 (92%) objectives in 2022/23. Work continues to re-engage both patients and professionals which has so far proven successful. This is evident from the patient responses to feedback requests and the professional attendances at meetings, including the re-established Steering Group and the education sessions. The network has also made progress with a data plan, a PD data project has been completed, a transplant project is being tested and further projects are planned.

Lead Clinician update

The past year has continued to be an active year for SPRUN with engagement throughout the network. Professional and patient engagement is central to achieving

our objectives and key to progressing the work of our network.

The ongoing informative and diverse education programme continues to be well attended with much enthusiasm both from the variety of speakers and also attendees. We also had a successful Patient First session demonstrating that our patients and families remain central to the goals of the network and to all we seek to do in supporting the delivery of care throughout SPRUN. Our collaborative work with Kidney Kidneys Scotland continues with the availability of electronic forms of two of our patient books – Transplant Journey and Facing Dialysis.

We have also managed to progress with data collection in the network focusing on initial small projects. Peritoneal dialysis (PD) for families is an immense undertaking and the initial data analysis is clearly powerful in showing the issues involved in delivering this care throughout Scotland. A further transplant work-up data project is also ongoing.

I look forward to another year to progress the tasks of the network and I am thankful to all professionals and families for their involvement and support and for enabling us to demonstrate, in this past year, the role and purpose of SPRUN.

Highlights

Education

SPRUN monthly 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 each year are 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.

9 sessions have taken place in 2022/2023. More information on these sessions is included below:

Date	Title	Attendees	Views	Number of boards represented
26/04/22	Genetics Teaching Session	16	50	7

20/05/22	Chronic Kidney Disease Study Day	31	12	9
28/06/22	Antenatally Detected Renal Anomalies Teaching Session	26	10	7
30/08/22	Hypertension Teaching Session	36	5	12
29/09/22	Patient First Session	20	26	6
31/10/22	Tubulopathies Teaching Session	22	11	10
29/11/22	Transplant Study Day	42	14	9
31/01/23	Miscellaneous Topics Teaching Session	23	7	7
30/03/23	UTI/Reflux Nephropathy Teaching Session	38	N/A	11

All sessions now use a standard survey to evaluate them. A summary and feedback from 2022/23 sessions are below:

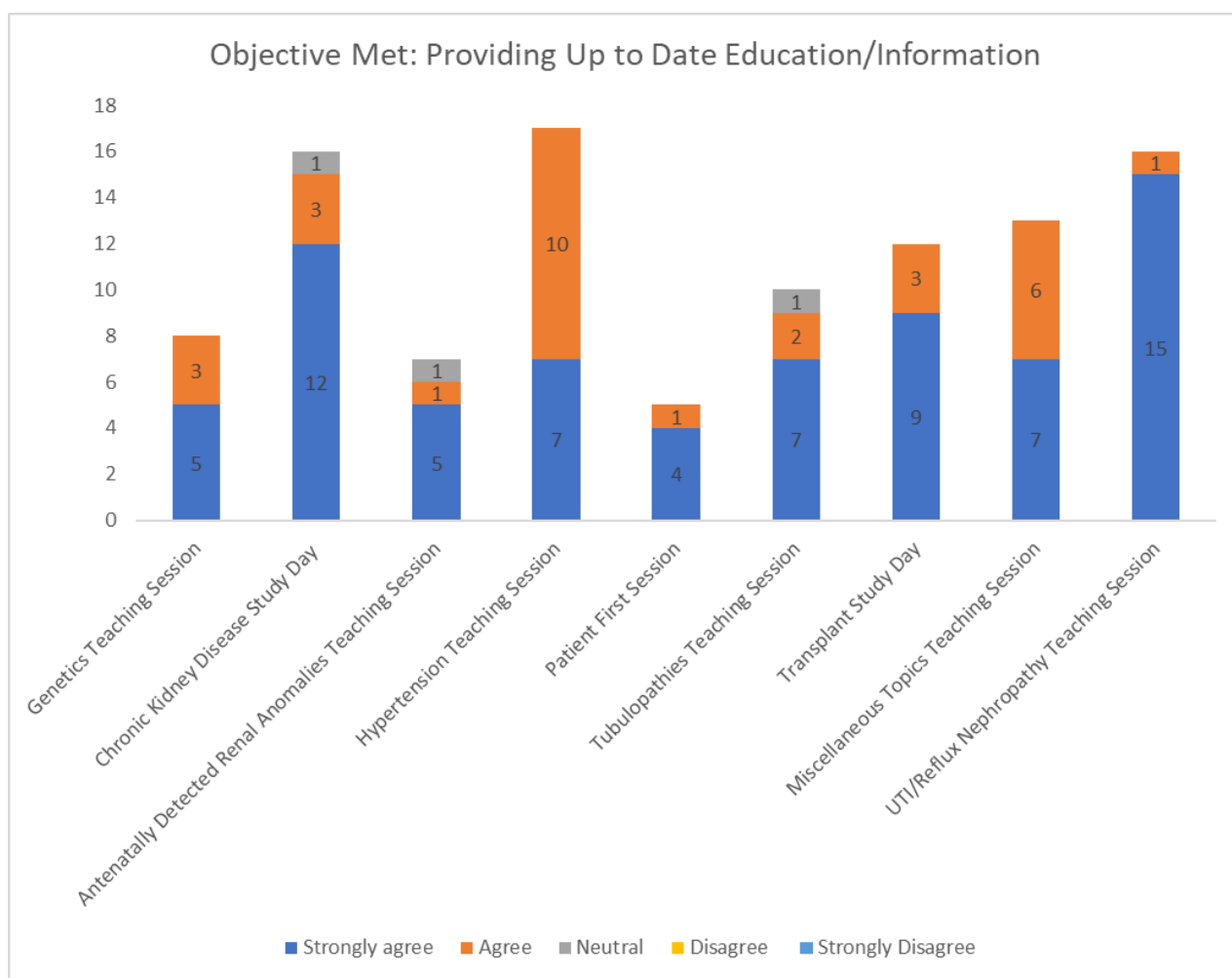


Figure 1 – Was the event objective met? All events 2022/2023

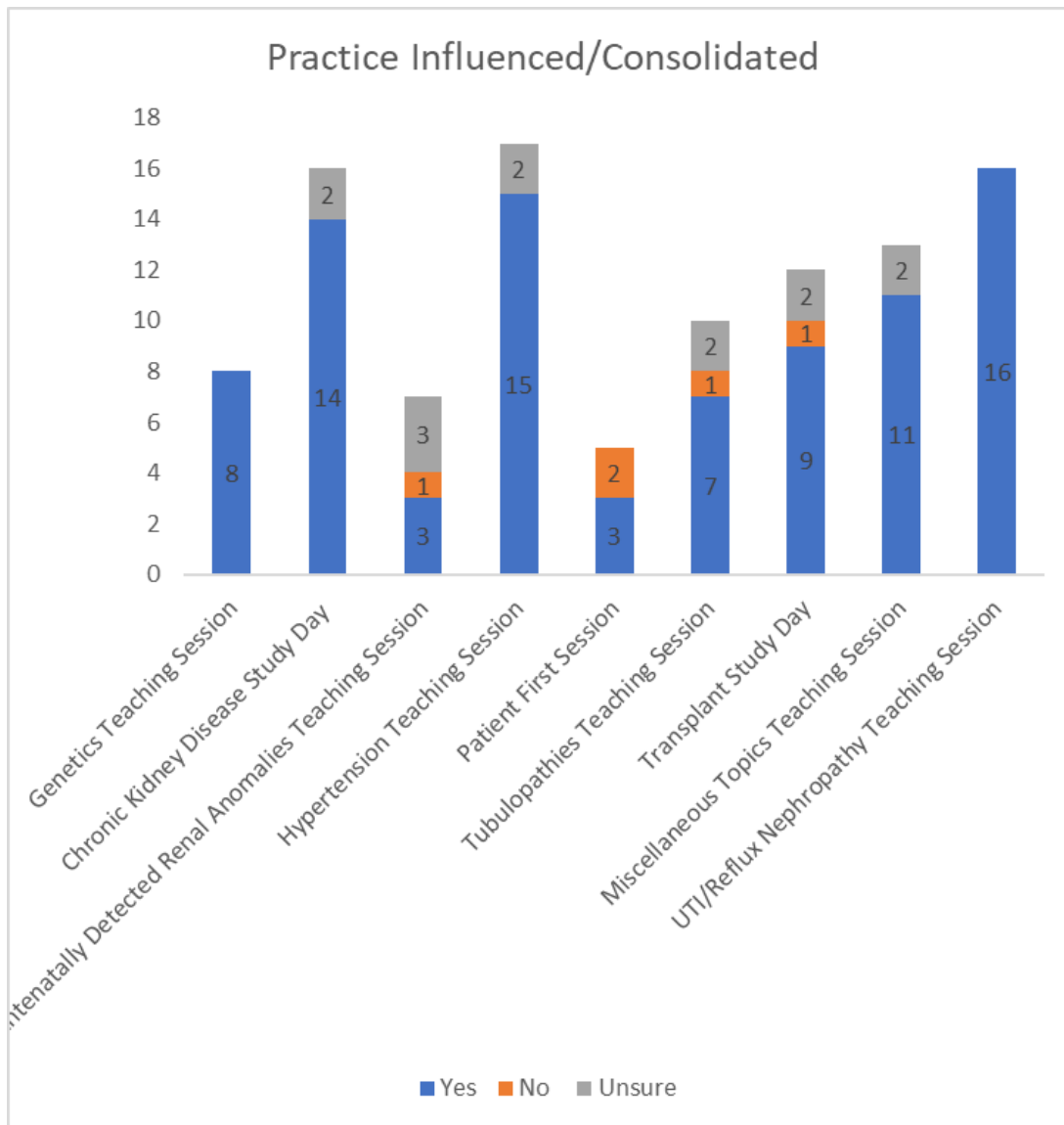


Figure 2 – Was your practiced influenced / consolidated

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 are also vital for the development on the new education strategy planned for 2023/2024.

Some specific feedback received from attendees is below:

“Can advise colleagues more confidently with regards to interpretation of common, uncomplicated renal findings on antenatal scans and look forward to the revised guideline for further introspection and improvement on my practice.”

“Absolute better understanding of parents view of a situation when unfortunately their child/children are admitted to hospital and transferred to bigger city hospital and their 'normal' has been taken away from them, home, school & family.”

“Great thoughts about plant based diets especially”

2022/23 was the final year of the current cycle of education sessions. A new education strategy will be developed in 2023/24.

Patient experience

A number of objectives in 2022/23 were set up to understand or improve patient experience. A Patient Reported Experience Measures (PREM) questionnaire was delivered by the Paediatric Renal team in RHC Glasgow. This standard questionnaire was designed by Kidney Care UK and was extended to all 13 paediatric renal centres in the UK. As well as providing feedback on patient experience this questionnaire will allow for Scotland to benchmark services with the rest of the UK.

Following feedback from patients, two interactive “flipbooks” were developed to provide patients and their families with information on the journey to transplant and dialysis. These illustrated books cover topics such as why the procedure is necessary, what to expect before, during and after the procedures and post procedure advice. Both booklets were designed at the request of patients who felt that standard information booklets would be helpful. Both booklets have also been adopted and shared by Kidney Kids Scotland. It is hoped that these booklets will ensure that patients and families are better informed on both dialysis and transplant, an evaluation of these resources is ongoing, with only a small number received so far. This will continue into 2023/24.

Data

Data has been an issue for SPRUN for several years. Previously, it was hoped that access could be granted to SERPR for all health boards. This process has faced several long delays and no longer appears feasible. Due to these ongoing issues a fresh approach to data was agreed for SPRUN alongside the Information Management Service. The refreshed data plan for SPRUN included targeted smaller data projects which can be used to understand current practice, highlight variations and improve processes. This new plan begun with Peritoneal Dialysis (PD). A PD data set was agreed alongside the PD nurse, which allowed for the patient journey and processes at each stage to be mapped. Analysis of this data will allow for improvement measures to be put in place to improve the care of PD patients.

Initial analysis of the data so far has identified that there have been 20 PD patients since 2018. Of those 20 patients only 4 have been NHS Greater Glasgow and Clyde patients (figure 3). **Numbers have been combined into North, East, West (excluding GG&C) and GG&C due to the small numbers of patients in each board area*

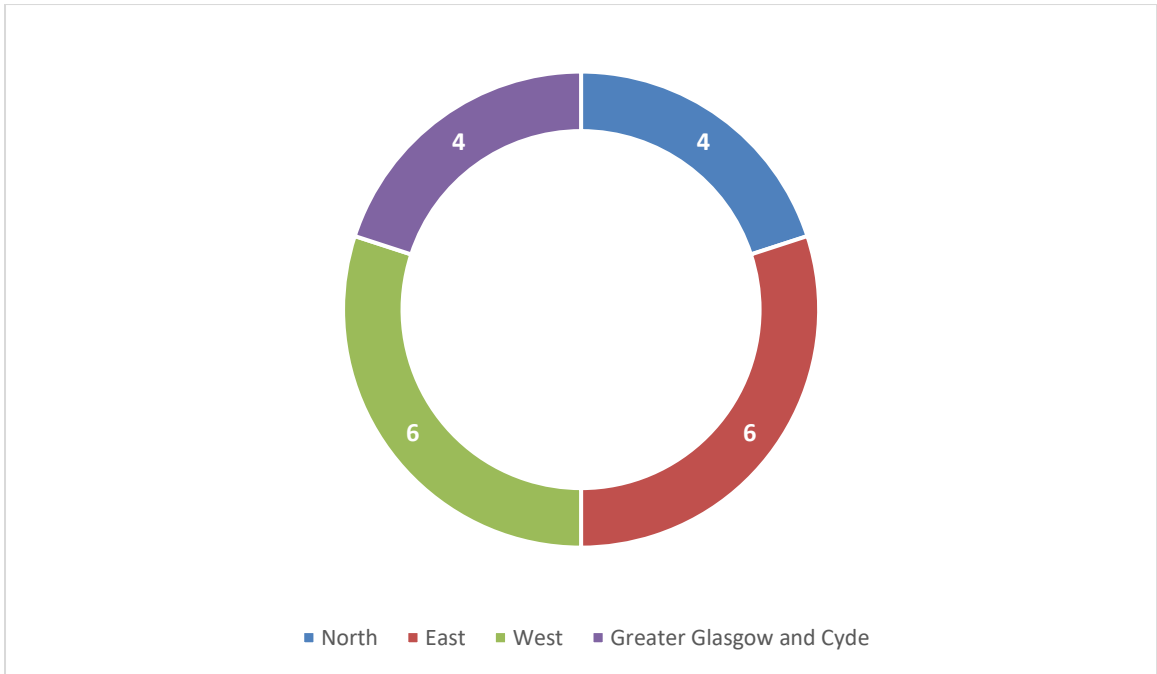


Figure 3 – split of PD patients by region

Despite only 4 patients being NHS GG&C residents, 18 of the 20 had to visit RHC, Glasgow for PD training. Resulting in 14 patients having to travel to RHC, Glasgow for their care.

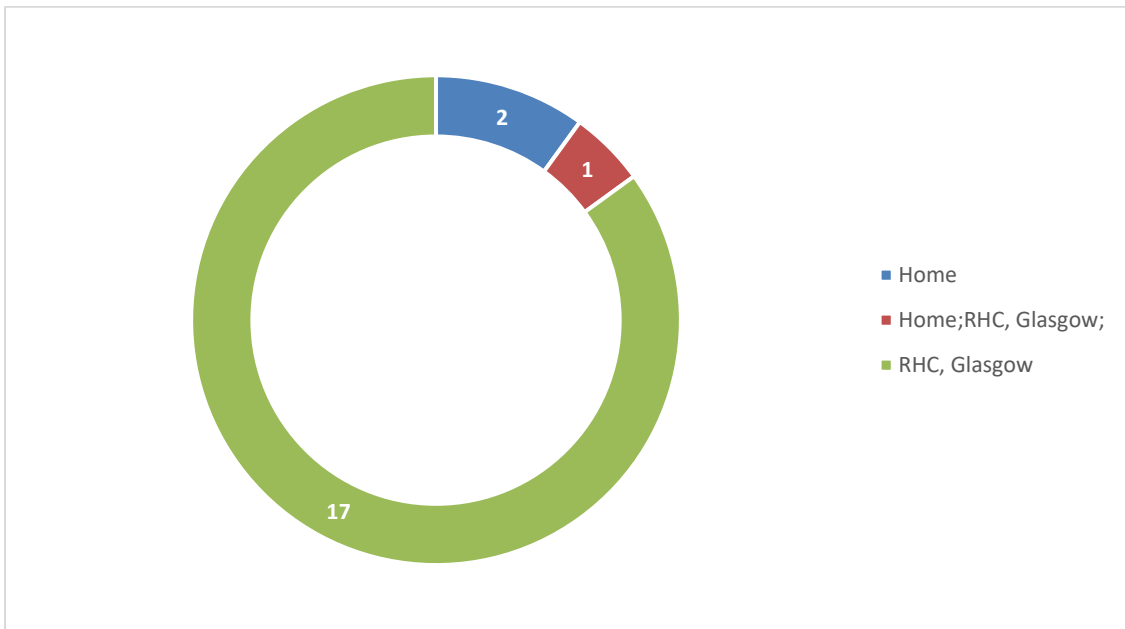


Figure 4 – location of PD training

Finally, the initial analysis of the data has identified that despite the low numbers these patients require a lot of time to manage. Of the 20 patients, 18 required at least weekly reviews. 13 of those 18 reviews took place in RHC, Glasgow with a further 5 having joint reviews with local services and RHC, Glasgow.

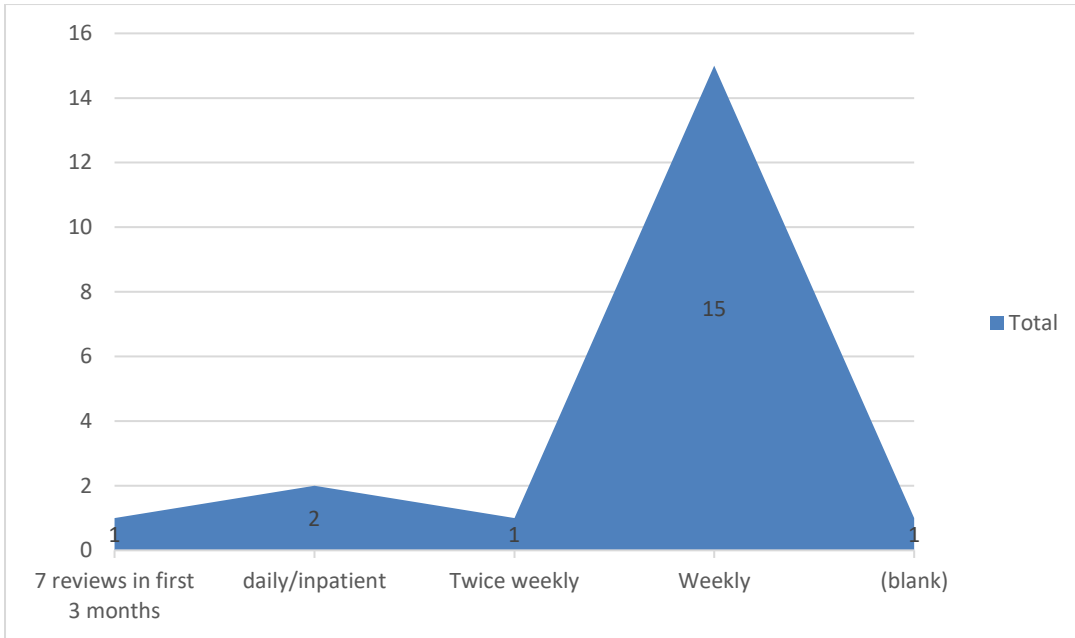


Figure 5 – frequency of PD review

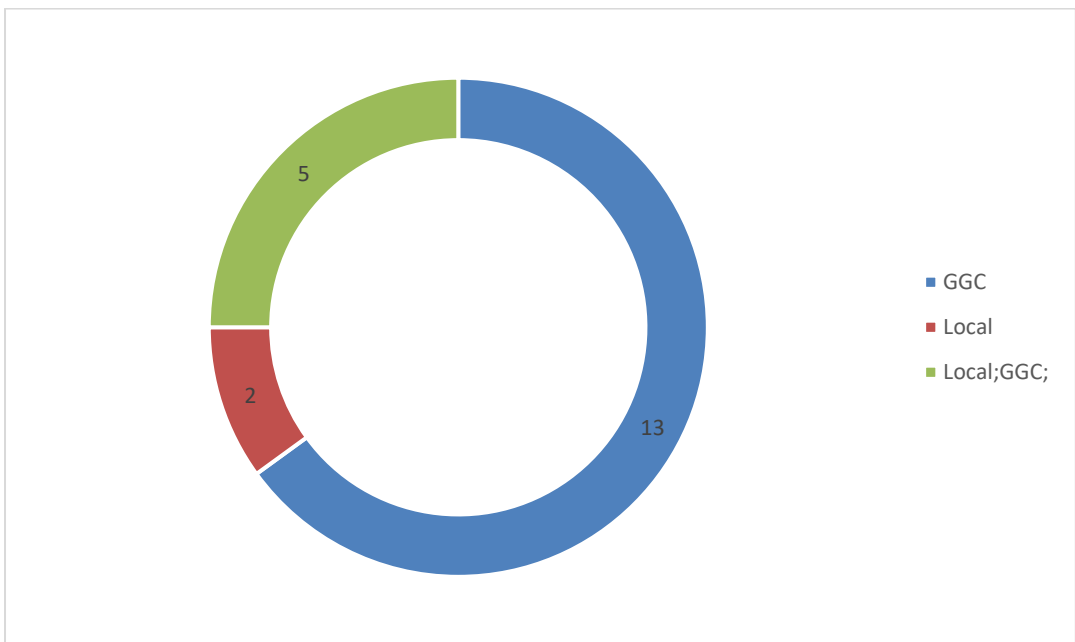


Figure 6 – location of PD review

Work is ongoing to analyse the data fully to develop an action plan to ensure as much of the care of these patients as possible is delivered locally.

A second data set for transplant data has been developed alongside IMS. This data set is currently being tested to ensure it meets the purpose it was designed for.

Service Developments

Several service development objectives were agreed as part of the 2022/23 workplan. Standards of Care for Renal and Urology patients had been in draft for a number of months and have now been agreed. It is hoped that this document will support teams to ensure an equity of care across Scotland. A baseline audit will be completed in

2023/24, this will allow the network to demonstrate any improvement from implementing these standards.

One objective to participate in a launch of the Paediatric Renal Transplant Service's (PRTS) extension to scope launch and to develop pathways of care for renal patients has not been possible to complete. There is an interdependency with the Specialist Services team and a PRTS launch being organised. This has not happened so far.

Looking forward – 2023/24

Looking forward to 2023/24 the plans for SPRUN include:

- Refresh of the SPRUN vision
- Refresh education strategy
- Audit the uptake and impact of revised Nephrotic Syndrome guideline
- Baseline audit of Standards of Care
- Continue with data plan

Finance

The finance spend for 2022/2023 is:

Development of “flipbooks” -	£188
Printing of patient resources -	£ 79
Total spend -	£267

Risks and issues

Engagement with PRTS

As highlighted above, an objective to develop pathways of care for renal patients has not been completed. This is due to an interdependency with the Specialist Services team and the PRTS extension to scope being launched.