

SPRUN Annual Report 2016/17



**Scottish Paediatric Renal Urology Network (SPRUN)**

**ANNUAL REPORT 2016/17**

Lead Clinician: Dr Craig Oxley/Dr Heather Maxwell

Network Co-ordinator: Ms Linda Watson

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## **Executive summary**

The Scottish Paediatric Renal and Urology Network (SPRUN) is a nationally designated Managed Clinical Network (MCN) that was 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 progress of the network work plan from 1 April 2016 to 31 March 2017 is highlighted in this report.

## ***2016/17 Achievements***

- SPRUN Nursing Network re-invigorated with a new nurse lead appointed for renal as well as urology.
- Clean and Dry: Management of Bladder and Bowel Problems in Childhood study day held in October 2016.
- Fundamentals in Paediatric Nephrology Dietetic education event in association with VitaFlo held in November 2016.
- Renal Service Audit completed.
- New website developed.
- Patient information videos developed for DMSA and MAG3 scans.
- Evidenced excellent patient care provision in NHS Grampian highlighted through story posted by parent on Patient Opinion and local Health Board Facebook page.

## ***Plans for the year ahead***

Refresh network vision, structure, membership and activities based on a five yearly plan that will be reviewed as appropriate covering areas such as:

- Integrated IT systems.
- Transition.
- Patient and family involvement.
- Reducing variation.
- Raising Network profile.
- Education.

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## Introduction

This report details the progress achieved by SPRUN in the period 1st April 2016 - 31st March 2017. A proposed work plan for 2017-18 is also included.

Paediatric renal and urology services provide care to children and young people from across Scotland who have kidney and bladder/urinary tract related health issues.

Tertiary paediatric nephrology services are based at the Royal Hospital for Children (RHC) in Glasgow, which also hosts national services such as the nationally designated renal transplant service and the renal dialysis service. 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 outwith the combined renal clinics.

Tertiary paediatric urology services are provided by three centres in Scotland: Aberdeen, Edinburgh and Glasgow. The Paediatric Urologists in Scotland work closely together as a network 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.

## Aim/ Purpose/ Mission Statement of Network

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.

The purpose of the network is to facilitate clinical and other improvements in paediatric renal and urology disorders through delivery of objectives set by the National Specialist Services Committee (NSSC) for NHS Boards and SGHSCD within the national commissioning process.

## Report against Work plan

During 2016/17 the capacity of the network to develop and progress its work programme was constrained due to staffing challenges in key clinical services, which in turn had an effect on the clinicians' ability to support the network's objectives. As a result the network's key areas of work were focussed on a narrower range of activities than would ordinarily be the case. The key priorities for the network in 2016/17 included:

### ***a. Developing Capability for Renal and Urology Care in Scotland by Delivering Professional Education***

#### ***Multi-disciplinary Professional Education***

- The network supports ten monthly multi-disciplinary Continual Professional Development sessions delivered by the specialist nephrology team in NHS Greater Glasgow & Clyde. From April 2016 - March 2017, a total of ten monthly education sessions have taken place.
- A joint multi-disciplinary education day with SPRUN and the Scottish Paediatric Adolescent Rheumatology Network (SPARN) took place on 08.11.16.

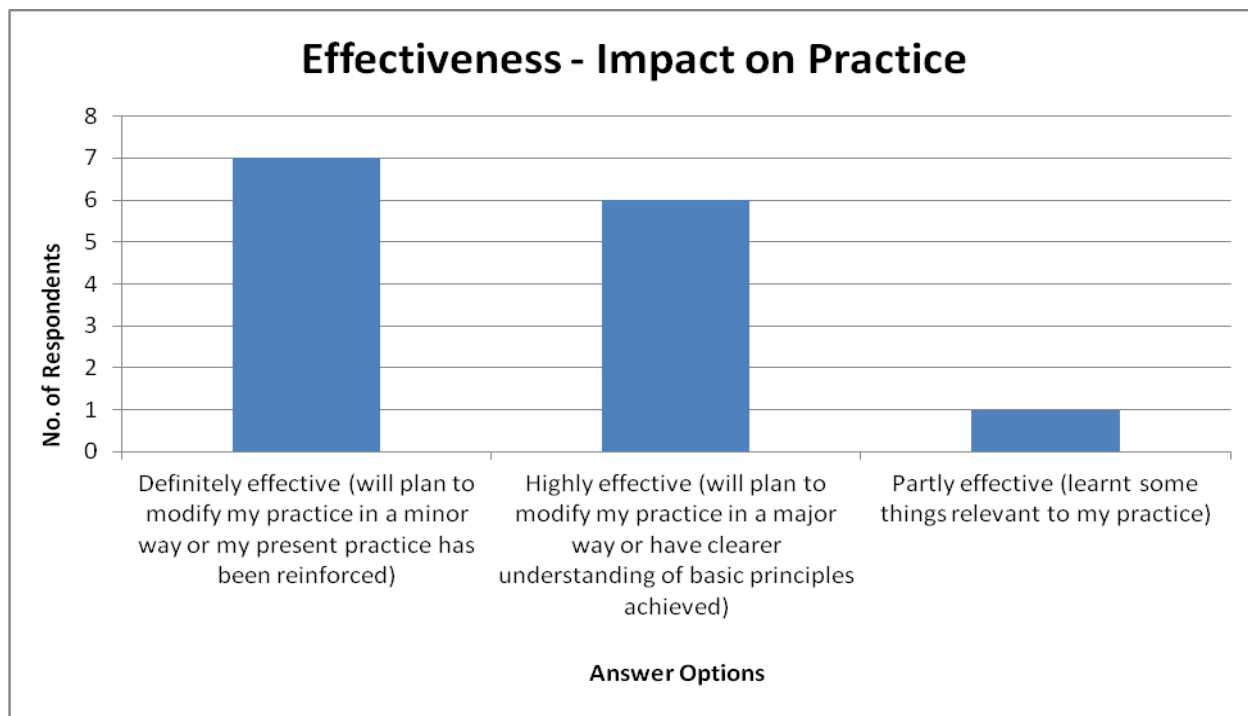


Figure 1: SPRUN/SPARN Multi-disciplinary Educational Day – Evaluation

**The Fundamentals in Paediatric Nephrology Meeting**

An education session for dietitians was held in Glasgow on 23 November 2016, based on a similar event hosted by the East Midlands, East England and South Yorkshire (EMEESY) renal network in October 2015. The event was held in association with Vitaflo UK and was opened up to the multi-disciplinary renal and urology teams across Scotland. Delegates rated the education as very useful and suggested that the event had a positive impact on their clinical practice.

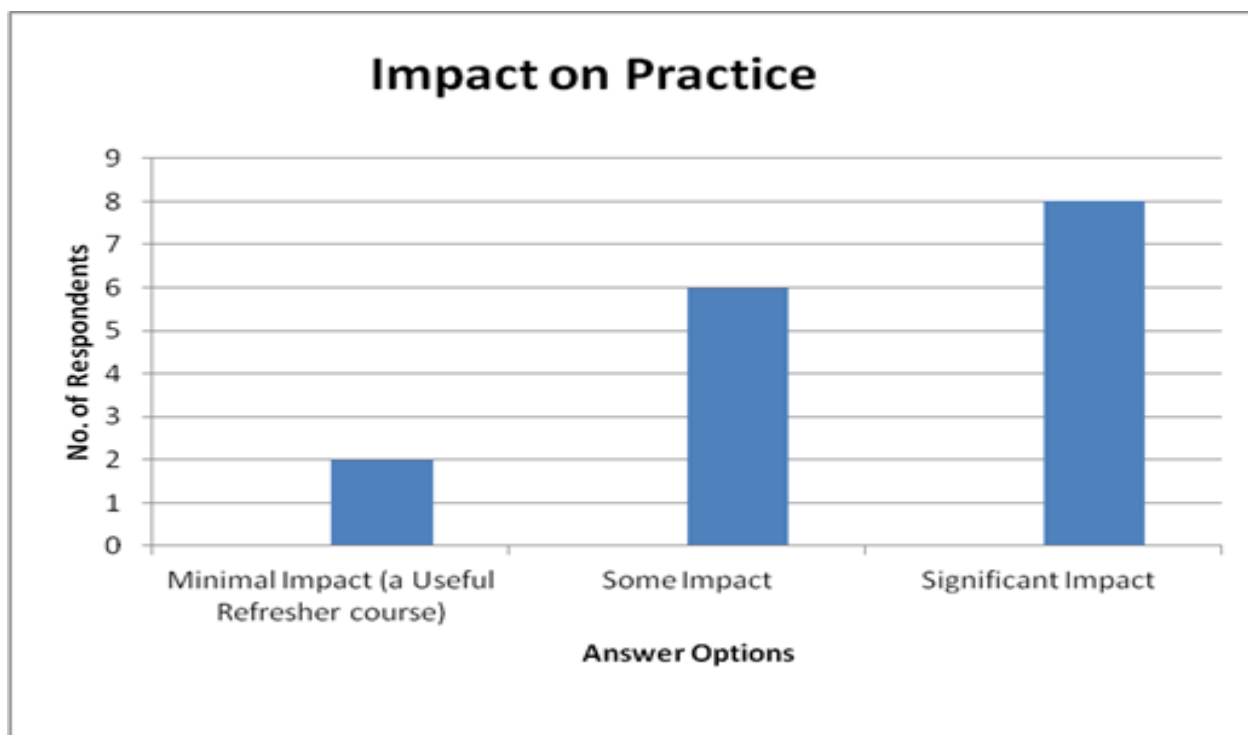


Figure 2: Fundamentals in Paediatric Nephrology Meeting – Evaluation

## b. Information Provision to Support Clinicians and Service Users

### **New Website**

SPRUN established an Editorial Group to develop a new network website that provides easy access to key information in a more interactive and user friendly way. Some additions to the website include an interactive map of combined renal clinics across Scotland, an events calendar, links to educational activities that parents may want to do with their children, informational videos about scans (please see below for more detail) as well as other patient information materials. The new website was signed off by the SPRUN Steering Group in March 2017 following positive feedback. The website address is [www.sprun.scot.nhs.uk](http://www.sprun.scot.nhs.uk).



The new site will continue to be promoted and developed further based on user feedback. Web usage statistics will be used to monitor ongoing use of website.

### **Patient Information Videos**

Two patient information videos explaining what to expect when attending hospital for MAG3 and DMSA scans were developed in partnership with the What Why Children in Hospital charity. The videos were completed in March 2017 and help support and prepare patients and families in relation to the tests being conducted.



Since the videos were published in early March, the MAG3 and DMSA videos had received 1297 and 815 views, respectively, on YouTube. Feedback so far has been extremely positive:

“These videos created ....., are really amazing & certainly very helpful to children and parents to eliminate their fears and clear their doubts! Great job! Thank you....”

These videos are also available via the SPRUN, What Why Children in Hospital and Vimeo websites.

### **Business Cards**

Following renal service audit feedback in 2013/14, SPRUN has been developing business cards to provide key service contact details for patients and families. The final draft of the SPRUN Business Card was approved by the Steering Group in March 2017 and the cards are due to be printed in early 2017/18.

**c. Data and Continuous Quality Improvement (CQI)**

**Data Capture**

Six clinics in the West of Scotland have access to the Strathclyde Electronic Renal Patient Record (SERPR), an IT system that works across boards and enables local multi-disciplinary teams in these areas to share patient information with the nephrologists supporting the delivery of clinics. For patients outwith the West of Scotland, information can be input into SERPR but local clinicians do not have routine access to SERPR’s comprehensive patient record. Likewise, they are unable to update any locally available information between clinic visits.

Work continues towards improving access to relevant clinical information across Scotland. Third sector financial support is available to help with providing remote access to SERPR beyond the West of Scotland region. This is being explored with NHS Greater Glasgow & Clyde who host SERPR on behalf of the West of Scotland Health Boards. Other avenues for providing improved access to relevant clinical data across Health Board boundaries are also being explored, e.g. by allowing visiting nephrologists remote access to other existing NHS systems such as Clinical Portal.

**Quality Indicators**

SPRUN had agreed four quality indicators to provide evidence of improvements in the quality and equity of service provision across Scotland.

**QI 1 - Care Delivery in a Local Setting.**

The network had previously successfully implemented a model of providing access to tertiary nephrology expertise through ‘combined renal clinics’ held in local hospitals in most Scottish health boards. These are multi-disciplinary where possible and include a local paediatrician and nurse with input from a visiting tertiary nephrologist. Figure 3 gives an overview of the percentage of children and young people that are seen at a renal clinic within their own Health Board area in 2014 - 2016.



Figure 3: Renal Clinic Attendance within Patient Health Board of Residency

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As highlighted above, recording of patient information in SERPR is not routinely available outwith the West of Scotland. As such, figure 3 may underreport combined renal clinic attendance in areas outside of the West of Scotland.

### QI 2 - Record all eligible patients in Scotland who have been offered access to PatientView

PatientView (PV) is a secure website that patients can log in to view their own person health information (e.g. clinic letters or lab results) to support self management and to improve long term patient outcomes. PV is currently available to all paediatric renal patients attending the combined clinics across Scotland.

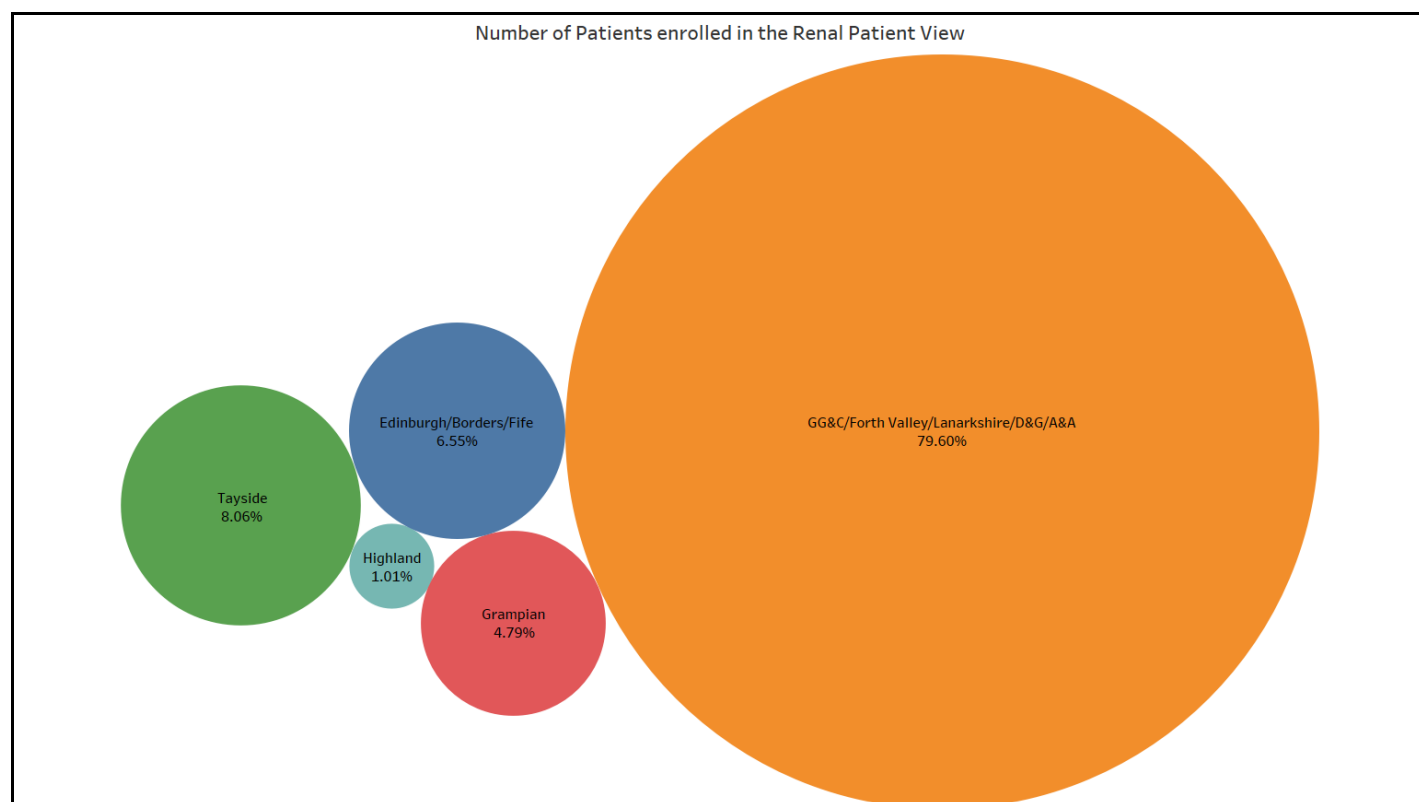


Figure 4: Patients enrolled in PV by Region/Board

Figure X clearly shows a difference in the uptake of PV between areas where SERPR is being used and those where it is not. This reflects the fact that PV is populated by SERPR data and therefore of limited value in areas where SERPR is not available.

### QI 3. - Distribution of Renal Medication Booklet to all eligible patients.

The Renal Medication Booklet (RMB) continues to be issued to patients on two or more medications. Renal Service Audit 2016/17 responses suggest that 22% of patients were using the RMB, more than double than in the 2013/14 audit where only 10% of respondents were using the RMB.

### QI 4 - Transition to Adult Care

According to feedback from the Renal Service Audit 2016/17 (please see below for more detail on the audit), 64% of the 50 patients aged 12 years or older had discussed transition to adult services in clinic.



**d. Patient Engagement**

**National Renal Service Audit 2016/17**

The second round of the National Renal Service Audit was conducted between April 2016 and January 2017, building on a previous audit undertaken in 2013/14. The aim of the audit is to obtain service users' views to gauge progress in terms of service delivery and service quality, and to identify key patient/family priorities for the network to work on going forward.

127 patients/carers were surveyed in the 2016/17 Audit, compared to 123 patients/carers in the 2013/14 Audit. Figure 5 gives an overview of clinic experience by clinic Health Board, comparing 2013/14 and 2016/17 results for each area. Overall patient experience was reported to be very positive.

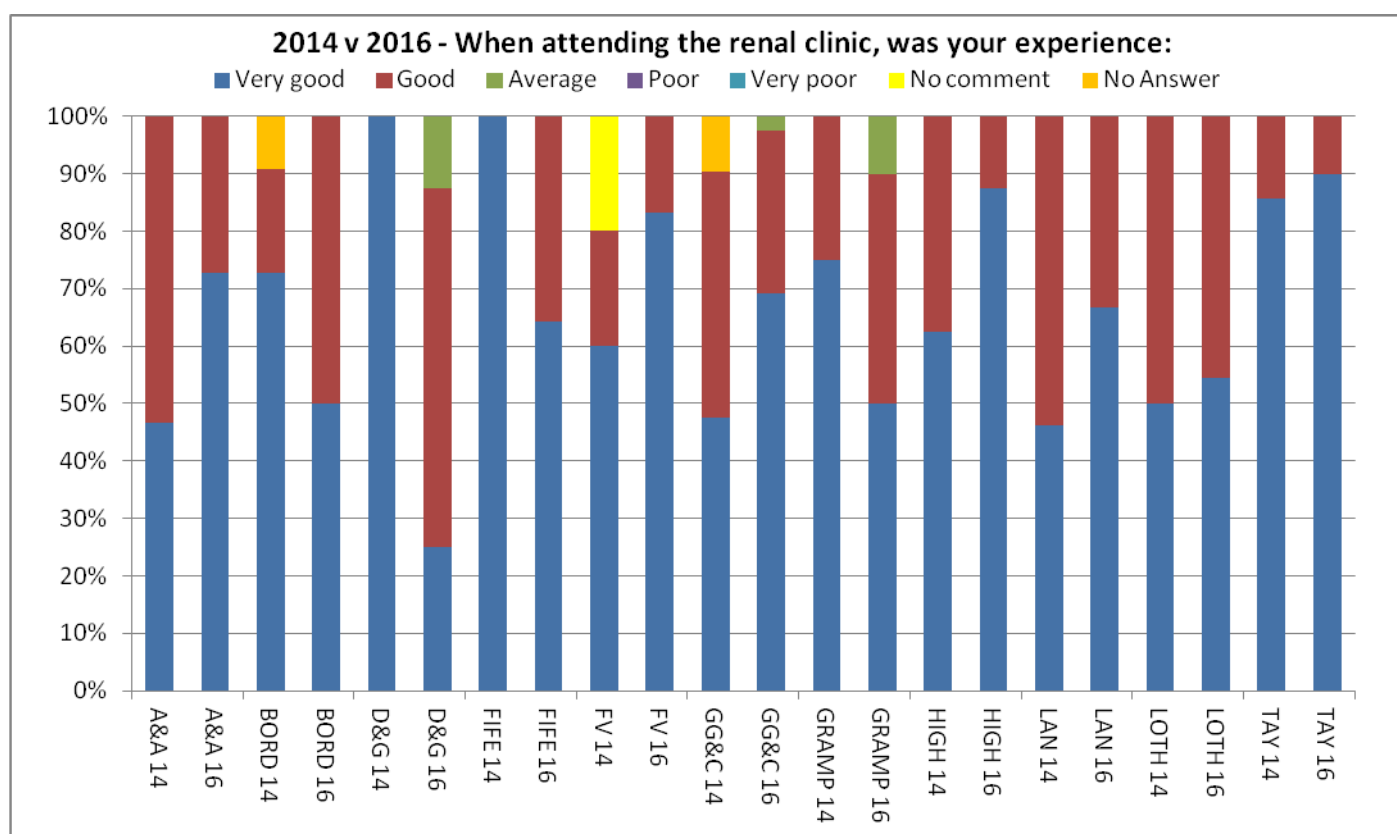


Figure 5: Clinic Experience by Health Board

**Plans for the year ahead**

Refresh network vision, structure, membership and activities based on a five yearly plan that will be reviewed as appropriate covering areas such as:

- Integrated IT systems
- Transition
- Patient and family involvement

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- Reducing variation
- Raising Network Profile
- Education

### **Network governance**

The network has agreed Terms of Reference that are currently being updated.

Dr Craig Oxley's term of Lead Clinician expired in September 2016 and Dr Heather Maxwell was appointed to the post on 31<sup>st</sup> January 2017.

SPRUN has begun to revise its structure and refreshed its nursing subgroup with new nursing leads for both renal and urology being identified.

### **Risks or issues**

Access to data continues to be challenging for the network. Through the service data manger in the West of Scotland, SERPR data is available to the network for audit purposes but as stated on page 5 this system does not currently cover the whole of Scotland. In addition, there is at the moment not sufficient clarity about the extent to which the service data manager can support the network's data needs and how best she can work in partnership with the Information Management Service in the National Network Management Service on this.

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### Detailed Description of Progress over Reporting Period

SPRUN have recognised that there is a need for a substantial revision of their workplan. As such, the items listed as amber will not be carried over as they are to the 2017/18 workplan but elements may be progressed as part of different workstreams in the refreshed workplan if this is considered appropriate.

Objective Number	Smart Objective	Linked Dimensions of Quality	Planned start/end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 31/03/2017	Anticipated Outcome	RAGB status
2015-01	Revisit renal/urology condition list and referral pathways  Provide guidance on where and when patients with renal /urology conditions through the development of a pathways document	1,2,3,4,5,6	01/04/2016 to 31/03/2017	N  Craig Oxley	Condition Review List completed following steering group meeting on 25.11.15.	Patients are seen by the appropriate clinicians at the appropriate times.	<b>A</b>
2015-03	Documenting the epidemiology of CKD & Transplant Patients	2,3,5,6	01/04/2016 to 31/03/2017	N  Craig Oxley	11/03/2015 - Tableau document completed. Further amendments required in relation to deprivation scale and distance travelled to clinics by patients. Distance travelled included in draft produced in November 2015.	Identifying potential service improvements.	<b>A</b>

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Objective Number	Smart Objective	Linked Dimensions of Quality	Planned start/end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 31/03/2017	Anticipated Outcome	RAGB status
2015-08	Implement actions from 2013/14 National Renal Service Audit	1,3,5	01/04/2016-31/03/2017	N Linda Watson	Business cards - draft completed, content updated for the majority of Boards, will be printed once all information received. Patient Pack to be revisited with patients, families and voluntary sector.		<b>A</b>
2016-01	Monitoring by annual benchmarking the delivery of combined renal clinics across Scotland with local network members and specialist team	1,2,3,4,5,6	01/04/16 to 31/03/17	Y	Dates for 2016/2017 clinics available.	Ongoing high quality multi-disciplinary clinics. Appropriate health professionals at clinics providing clinics closer to home.	<b>B</b>

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Objective Number	Smart Objective	Linked Dimensions of Quality	Planned start/end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 31/03/2017	Anticipated Outcome	RAGB status
2016-02	Provide educational opportunities through: <ul style="list-style-type: none"> <li>• 2 national MDT days</li> <li>• 10 monthly CPD sessions</li> </ul>	2,3,4,5,6	01/04/16 to 31/03/17	Y David Hughes	Ten monthly CPD sessions held. A national event took place in conjunction with SPARN in November 2016. Additional national multi-disciplinary events supported by SPRUN covered topics related to bladder, bowel and diet. Education was also built in to the nursing meetings.	Professionals providing renal and urology care to children have increased knowledge/confidence.	<b>B</b>
2016-03	Repeat National Renal Service Audit	1,3,5	01/04/2016-31/03/2017	N Craig Oxley, & Linda Watson	Questions were reviewed and amended following previous audit. Re-audit completed with patients and families at clinics across Scotland. Results available.		<b>B</b>

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Please develop and update the table below to include the network's designation objectives and related agreed annual objectives. When planning for the year ahead, please consider the standard statements in the guidance section to inform the development of annual network objectives.

### RAG status key

RAG status	Description
<b>RED (R)</b>	The network is unlikely to achieve the objective/standard within the agreed timescale
<b>AMBER (A)</b>	There is a risk that the network will not achieve the objective/standard within the agreed timescale, however progress has been made
<b>GREEN (G)</b>	The network is on track to achieve the objective/standard within the agreed timescale
<b>BLUE (B)</b>	The network has been successful in achieving the network objective/standard to plan

The Institute of Medicine's six dimensions of quality are central to NHS Scotland's approach to systems-based healthcare quality improvement; therefore objectives should be linked to these dimensions:

1. **Person-centred:** providing care that is responsive to individual personal preferences, needs and values and assuring that patient values guide all clinical decisions;
2. **Safe:** avoiding injuries to patients from healthcare that is intended to help them;
3. **Effective:** providing services based on scientific knowledge;
4. **Efficient:** avoiding waste, including waste of equipment, supplies, ideas, and energy;
5. **Equitable:** providing care that does not vary in quality because of personal characteristics such as gender, ethnicity, geographic location or socio-economic status; and
6. **Timely:** reducing waits and sometimes harmful delays for both those who receive care and those who give care.

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### Proposed Workplan – SPRUN 2017-2018

Objective Number	Smart Objective	Linked Dimensions of Quality	Planned start/end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 31/03/2018	Anticipated Outcome	RAGB status
2017-01	<p>Ensure that patients' and families' views influence the work of the network through:</p> <ul style="list-style-type: none"> <li>- the development of a patient engagement strategy designed in partnership with patients and families to reflect their preferred engagement methods</li> </ul>	1,5	March 2018	No		The views of patients/ families and what is important to them are reflected in the work plans and strategic direction of SPRUN	
2017-02	<p>The network will design and deliver a programme of education that meets the needs of multidisciplinary staff delivering paediatric renal and urology services by:</p> <ul style="list-style-type: none"> <li>- undertaking a</li> </ul>	2,3,4,5	March 2018	No		Multidisciplinary staff delivering paediatric renal and urology services have increased knowledge/ confidence	

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Objective Number	Smart Objective	Linked Dimensions of Quality	Planned start/end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 31/03/2018	Anticipated Outcome	RAGB status
	learning needs analysis to inform the development of an education strategy - delivering a multidisciplinary education day						
2017-03	The network will work to reduce variation in the measurement of blood pressure by: - scoping existing practice in different areas - developing an Investigation and First Line Management Guideline - identifying key audit measures associated with the guideline	1,2,3,4,5,6	March 2018	No		Patients receive standardised care based on evidence and best practice	
2017-04	The network will work towards developing an approach to transition by:	1,2,3,4,5,6	March 2018	No		Development of a consistent approach to transition that	



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Objective Number	Smart Objective	Linked Dimensions of Quality	Planned start/end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 31/03/2018	Anticipated Outcome	RAGB status
	- scoping the transition arrangements that currently exist in each area					meets the needs of young people moving from paediatric to adult services.	
2017-05	The network will identify where electronic information is stored about renal and urology patients by mapping out the systems used by the various professionals involved in each health board area.	2,3,4,5,6	March 2018	No		Electronic patient information is available to clinicians when needed.	
2017-06	The network will ensure that it is properly organised and supported to deliver its objectives by:  - establishing a working model - developing a communications strategy to ensure engagement of all	3,4,5,6	March 2018	No		Effective delivery of network objectives with the engagement of all relevant stakeholders.	

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Objective Number	Smart Objective	Linked Dimensions of Quality	Planned start/end dates	Detailed Plan Available / Owner	Description of progress towards meeting objective as at 31/03/2018	Anticipated Outcome	RAGB status
	stakeholders						
2017-07	<p>The network will ensure that all stakeholders are clear about its purpose and aims by:</p> <ul style="list-style-type: none"> <li>- agreeing and sharing a vision and 5 year work plan</li> <li>- reviewing and agreeing the scope of the network</li> </ul>	3,4,5,6	March 2018	No		All stakeholders are clear about the goal of the network and their role in achieving it.	

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### Appendix 1: Network Membership and Contacts

Health Board	Member/Contact	Designation
Ayrshire & Arran	Dr Bridget Oates	Consultant Paediatrician
Borders	Dr Andy Duncan	Head of Clinical Services Paediatrics and Child Health
	Mandy Stephens	General (Acute) Registered Nurse
Dumfries & Galloway	Dr Raj Shyam	Consultant Paediatrician
	Jill Lindsay	Community Childrens Nurse
Fife	Dr Evelyn Menzies	Associate Specialist Paediatrician
Forth Valley	Karen Macfarlane	Paediatric Sister/Renal Link
	Caroline McAlpine	Continance Nurse for Children
Grampian	Dr Craig Oxley	Consultant Paediatrician
	Lynne Riach	Paediatric Renal Clinical Nurse Specialist
	Mr Chris Driver	Consultant Surgeon & Urologist
	Marion Hird	Clinical Nurse Specialist in Paediatric Urology
Greater Glasgow & Clyde	Dr Heather Maxwell	Consultant Paediatric Nephrologist
	Dr David Hughes	Consultant Paediatric Nephrologist
	Dr Ihab Shaheen	Consultant Paediatric Nephrologist
	Angela Lamb	Paediatric Renal Pharmacist
	Susan Burns	Renal Data Manager
	Dr Louise Pittendrigh	ST7
	Fiona Graham	Paediatric Renal Dietitian
	Jacki Smart	General Manager Surgery
	Ursula Monachan	Advanced Paediatric Nurse Practitioner (Renal)
	Ms Boma Lee	Consultant Paediatric Surgeon & Urologist
	Dr Amita Sharma	Consultant Paediatrician
Highland	Dr Alan Webb	Consultant Paediatrician
	Dr Janaki Vedarajan	Speciality Doctor in Paediatrics
	Patricia Rankine	Community Children's Nursing Team Leader
Lanarkshire	Dr Thin Thin Saing	Associate Specialist Paediatrician
	Dr Fiona Cameron	Associate Specialist Paediatrician
Lothian	Dr Rozi Ardill	Consultant Paediatrician
	Dr James Donnelly	Locum Consultant Paediatrician
	Gillian Walker	Renal Dietitian Team Lead
	Tracey Mcgregor	Renal Nurse Specialist
Tayside	Dr Catriona Morrison	Consultant Paediatrician
	Sandra Lloyd	Paediatric Renal/Enuresis Nurse
Third Sector/Family Representation	Member/Contact	Designation
Kidney Kids Scotland	Sheena Dunsmore	Manager
Parent	Rebecca Hemingway	N/A
Parent	Mark Glendinning	N/A

## Appendix 2: Finance

The network was allocated £5,000 from Specialist and Screening Directorate (NSD) for 2016/17.

This has been spent as follows:

### Network Spend

Description	Finance
Patient Information Videos	£3,500.00
Printing	£ 309.00
Network Meetings	£ 855.00
<b>Total</b>	<b>£4,664.00</b>