

‘THINK KIDNEYS’

Email update for everyone involved in Transforming Participation in Chronic Kidney

August 2016, no.5

Rachel Gair, Person Centred Care Facilitator and Sarah Evans have produced this month's update

Welcome

This is a really exciting time for the TP-CKD programme as we come to the end of phase 1 which has been about embedding measurement. We have demonstrated that this is feasible and we now move onto phase 2 which is about spread and sustainability. We hope the data that we have made available to each unit will help in moving onto the next phase.

CS-PAM

Each unit in cohort 1 will now have received an individual renal unit report, an overall cohort report and confidential individual scores. You will also have received a framing document with suggestions on how the reports may be used.

Some units are taking the key messages from the reports and presenting them to their MDT. It would be great to hear from others how they plan to use the data within their units. Members of the core team would welcome an invitation to any of these meetings to help facilitate discussion and action plans or to help address any issues.

Patient View

The TP-CKD programme is very excited about the launch of the 'Your Health Survey' screens in PV. We would really like you to encourage those patients who have completed the surveys and who are on PV to access the screens. Using PV with this new addition has real potential to enable patients to lead and change conversations to a more person centred approach.

I would urge you to go onto PV and see what is available and encourage as many patients to register.

Clinician led data

This is now available to each unit lead as an excel spread sheet. We would welcome any comments on how this may be used in conjunction with PV to begin to change the conversation with the patient towards a more person centred approach.

Getting the Most from your Data

The above reports are designed as reflective rather than judgemental in nature and the project team felt it would be useful to provide support to the teams to develop a plan around these data. Part of that is to consider how to share the information from the results with the wider team of staff and

patients and to look at ways that the data can be used positively to develop your plans that will result in improvement. To support you with this important element of the programme we would like to visit some of the teams and facilitate a workshop to help you develop an action plan to deliver the changes you want to see.

In the first instance we will concentrate and work with a few units within cohort 1 with the aim of sharing and developing the learning wider across cohort 1 and 2. We will be in touch about dates for these workshops which we'd like to do during the autumn.

Cohort 2

Renal units are coming on board now and an event is planned to get them started on Tuesday 8 November 2016 in Birmingham. We'd like someone from your team to attend this event so Cohort 1 renal units can share their experiences of PAM/PROM and CS-PAM. We'll be in touch shortly with more details of this day.

PREM

The UKRR have been delighted with the response from units within England to the PREM which recently completed – it has been overwhelmingly positive and we would like to share with you an update on the pilot. The survey comprises 43 questions and was developed by members of our Measurement Workstream of the TP-CKD Programme. The survey also had input from kidney patient charities such as the National Kidney Federation, BKPA and the UKRR Patients' Council. The pilot PREM was sent to the 52 Renal Units in England.

The deadline for completing the PREM has now closed and all returns have been received, scanned and checked by the UK Renal Registry. We are very pleased with the response rate with 7,986 returns from 41 of the 52 Units – an amazing effort by every involved. You can find a list below of how many returns we received from each unit (appendix A). Now that all the surveys are in, work is due to begin on analysing the data. A report with all the findings will be shared with all units and published in November 2016.

It is very important for us to now capture the learning from this pilot of the PREM survey so that we can improve the process for next and subsequent years' of the survey. The UK Renal Registry has been working very closely with Newcastle upon Tyne Hospitals NHS Foundation Trust to capture their experiences, learning and outcomes – their case study will be published on the Think Kidneys website over the coming weeks so please keep an eye out for this.

We hope to gain as much information from cohort 1 about the challenges to implementation but also capture what went really well. This will help in delivering next year's PREM tool which will then have gone through a validation process.

Being the first year of PREM, this has really proved to be a great piece of work, so thank you to everyone involved thus far.

Other TP-CKD project news

- We're very pleased to have been successful in having poster presentations accepted at the American Society Nephrology conference in November and Leaders in Healthcare event in Liverpool 31 October – 2 November 2016.
- Sabine Vanderveer the co-chair of the Measurement Workstream will shortly be embarking on a TP-CKD tour visiting Aberdeen, Paris and Manchester to share and spread the word on PAM and PROM.
- NHS England agreed a deal to grant 1.8 million people access to the PAM tool as part of the developing Self Care Support programme, and invited local NHS organisations and their

partners to apply to use them. Thirty-eight bids - including a number of new care model Vanguards, and sites working as part of the Integrated Personal Commissioning (IPC) Programme, have been confirmed, which will see use of the tool spread across England and applied to help improve care and outcomes for a variety of different patient groups. You can access further detail about PAM from the NHSE [webpages](#)

The Website – www.thinkkidneys.nhs.uk/ckd

If you get chance to visit the website you will see lots of changes to content – particularly our personal stories. If you would like your story or thoughts to appear on the website, drop me an email and we can work together to get it published. I am happy to write it for you following a conversation or you can submit something you've written to me or Rachel. It's a great way to share your experiences as a person with CKD or as a clinician – everyone's experience is unique and valuable and creates learning and community – anniemtaylor331@gmail.com

Appendix A: Patient Reported Experience Measure (PREM) Returns

Renal Unit	City	Number of surveys distributed from UKRR to Renal Unit	Total Number of Returns	% of Returns based on surveys sent from UKRR
Freeman Hospital	Newcastle-upon-Tyne	1400	820	58.6%
Leicester General Hospital	Leicester	1340	513	38.3%
Churchill Hospital	Oxford	1310	402	30.7%
Lister Hospital	Stevenage	650	341	52.5%
Southmead Hospital	Bristol	650	332	51.1%
Kent & Canterbury Hospital	Canterbury	650	322	49.5%
Guy's and St Thomas's Hospital	London	650	287	44.2%
Northern General Hospital	Sheffield	650	284	43.7%
University Hospital Coventry & Warwickshire	Coventry	650	280	43.1%
Nottingham City Hospital	Nottingham	950	259	27.3%
Royal Derby Hospital	Derby	650	239	36.8%
St James's University Hospital	Leeds	650	227	34.9%
Royal Sussex County Hospital	Brighton	650	224	34.5%
St Luke's Hospital	Bradford	800	212	26.5%
Gloucestershire Royal Hospital	Gloucester	650	195	30.0%
King's College Hospital	London	650	194	29.8%
Addenbrookes Hospital	Cambridge	650	193	29.7%
Dorset County Hospital	Dorchester	1050	179	17.0%
Sunderland Royal Hospital	Sunderland	650	174	26.8%
Doncaster Royal Infirmary	Doncaster	650	173	26.6%
Cumberland Infirmary	Carlisle	650	167	25.7%
New Cross Hospital	Wolverhampton	650	155	23.8%
Aintree University Hospital	Liverpool	650	153	23.5%
Norfolk & Norwich University Hospital	Norwich	650	150	23.1%
Royal Berkshire Hospital	Reading	650	130	20.0%
Basildon University Hospital	Basildon	650	129	19.8%
Russell's Hall Hospital	Dudley	650	106	16.3%
Arrowe Park Hospital	Wirral	650	94	14.5%
Southend University Hospital	Southend	650	89	13.7%
Royal Cornwall Hospital	Truro	650	87	13.4%
Broomfield Hospital	Chelmsford	650	83	12.8%
Hull Royal Infirmary	Hull	650	83	12.8%
St Helier Hospital	Carshalton	1450	63	4.3%
University Hospital of North Staffordshire	Stoke-on-Trent	650	60	9.2%
Ipswich Hospital	Ipswich	650	58	8.9%
Manchester Royal Infirmary	Manchester	650	51	7.8%
James Cook University Hospital	Middlesbrough	750	49	6.5%
Royal Shrewsbury Hospital	Shrewsbury	650	34	5.2%
St George's Hospital	London	650	24	3.7%
Queen Elizabeth Hospital, Birmingham	Birmingham	650	17	2.6%
Royal Liverpool University Hospital	Liverpool	650	1	0.2%
INVALID (Unidentifiable due to missing RU Name / RU Code)	NA	NA	353	-
TOTAL		38150	7986	20.9%