

## Valuing Individuals: Transforming Participation in Chronic Kidney Disease King's College Hospital Renal Department Workshop

June 2017



Figure 1 Rachel Gair, Person Centred Care Facilitator meets some of the team the team at KCH

### Introduction

Rachel Gair, Person Centred Care Facilitator and Catherine Stannard, Programme Support Officer for the [TP-CKD Programme](#) ran a series of sessions and workshops with staff at King's College Hospital (KCH) Renal Department on Tuesday 13<sup>th</sup> June 2017. KCH have been instrumental in the TP-CKD programme, returning over 380 [Your Health Surveys](#) from across their dialysis and renal outpatient population as well as implementing a department-wide push for [Patient View](#) amongst their patients by the development of staff PV champions in each area and using Peer Support.

KCH were ideally placed to take part in the programme, having already collected Patient Reported Outcome Measures in their renal unit, as well as having one of the longest standing peer support programmes in the country. This has meant they have been able to build on what they already have in place, as well as share learning to the TP-CKD programme and other units involved.

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### Session 1: Bromley Satellite Unit

**Who did we meet?** *Paula Maloney, Senior Sister and Unit Manager*

The day began with a visit to Bromley Satellite Dialysis Unit, where the Senior Sister had implemented Your Health Survey amongst the majority of patients dialysing at the unit, and re-surveyed this patient population six-monthly over the last year.

Paula Maloney, Senior Sister and Unit Manager at Bromley, explained to the TP-CKD team how her staff have been collecting Patient Reported Outcome Measures (PROM) and entering them manually onto Renal Ware (KCH's internal renal patient record system) before returning the surveys to the UK Renal Registry. Symptoms are colour coded against severity on each patient. The results are then available to the Multi-Disciplinary Team and used at the quarterly Multi-Disciplinary Meetings (MDM) to inform their care planning. There are also Patient View champions within the unit.

#### Looking Forward:

- The TP-CKD team explored with Paula the idea of entering Patient Activation Measures (PAM) alongside the PROM data in Renal Ware, and the challenges this posed due to time lag in the UK Renal Registry processing and returning the PAM results
- It was agreed that Bromley Satellite Unit would trial using a web based PAM scoring sheet. This would allow the staff at Bromley to enter the PAM results in real time, before returning the Your Health Surveys to the UK Renal Registry for analysis
- The potential benefits of using the PAM within the MDM at Bromley unit were discussed, as well as the importance of the nursing team gaining an understanding of how PAM/PROM can be used when interacting with patients
- The TP-CKD team offered to return and feedback Bromley's data to the nurses at the unit, and discuss [ways of changing conversations with patients](#) based on their PAM/PROM results.

## Session 2: Academic Meeting

**Who did we meet?** Staff representatives from the Main Haemodialysis (HD), Satellite Haemodialysis, Transplant and Peritoneal Dialysis (PD) teams.

In this session, Rachel Gair from the TP-CKD Programme gave a presentation to the staff at KCH feeding back the data (PAM/PROM/PREM) that had been collected by them so far.

### Patient Activation Measure

The staff were shown a breakdown of PAM levels by modality. The graph shows, from the data collected so far, that the majority of Level 1 and Level 2 Activated patients were found in the HD population, with just over 50% of patients overall recorded as being at a Level 1 or Level 2 activation.

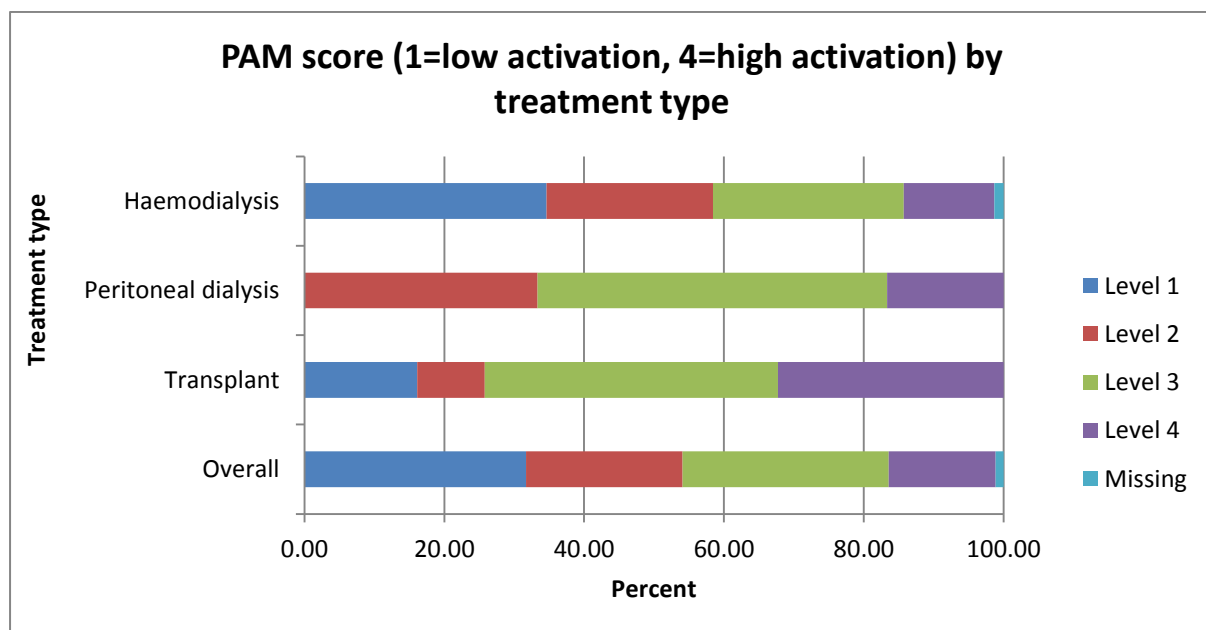
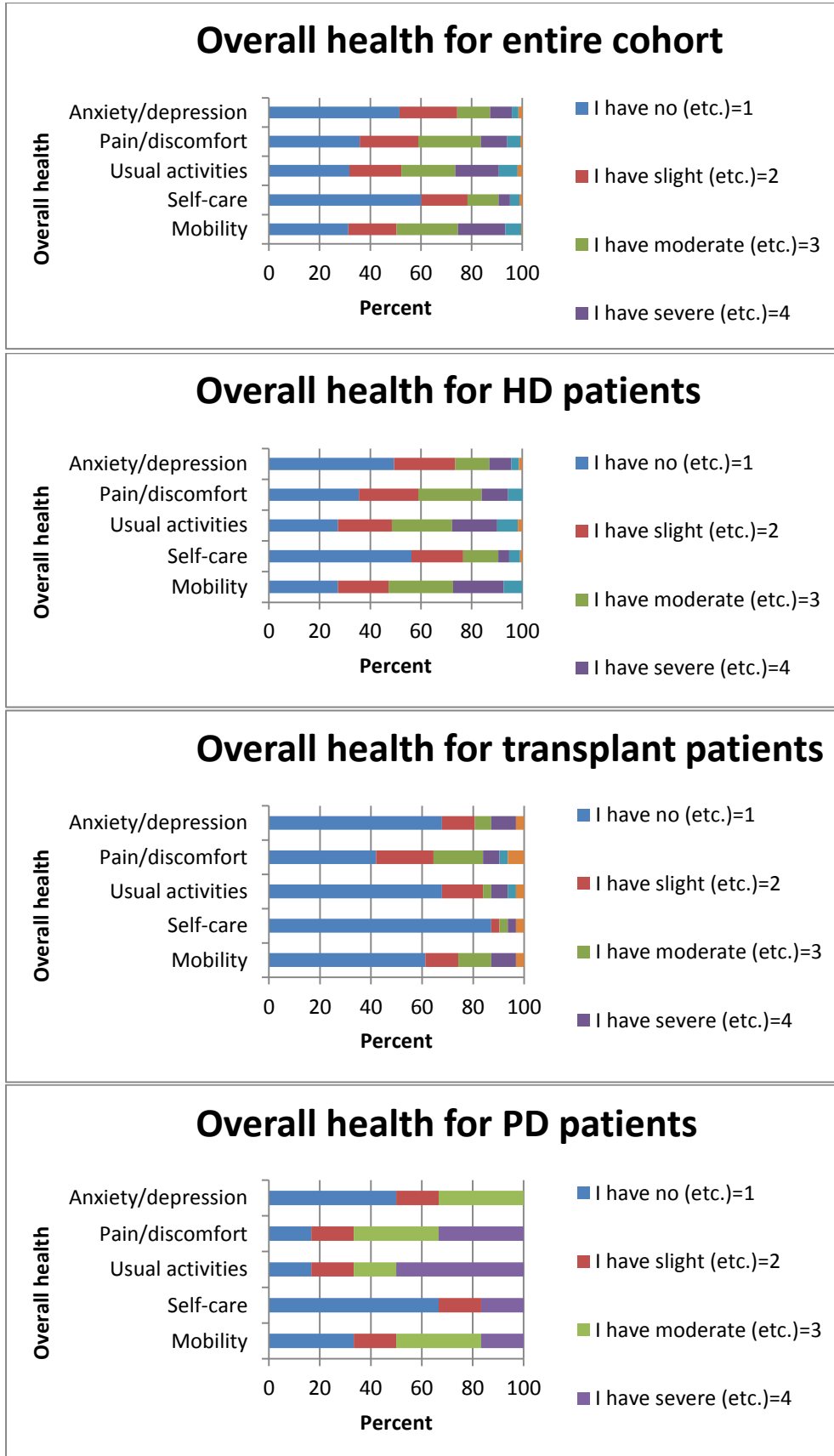


Figure 2 PAM level by treatment type

### Overall Health

Staff were then shown the patient's overall health results, which were compared by modality. Just under 50% patients overall reported moderate to extreme problems with mobility, which slightly increased when looking at the HD and PD patient responses. The majority of extreme problems were reported amongst HD patients. The Overall Health in transplant patients however was a lot better with a much smaller proportion of patients reporting moderate to extreme problems with their overall health and under 30% reporting moderate to severe problems with mobility.

Figure 3 Overall health by treatment type



**Symptoms**

When looking at the symptom burden for patients at KCH, weakness and lack of energy was reported to be the highest symptom burden with 60% patients reporting moderate to overwhelming weakness/lack of energy. The overwhelming symptoms were found mostly amongst the HD population.

The team discussed how these reported symptoms could be used within signposting, for example ensuring those with overwhelming feelings of being depressed, anxious or worried were seeing the renal counsellor or those with overwhelming poor appetite were seeing the dietician.

**Figure 4 Symptoms for overall cohort**

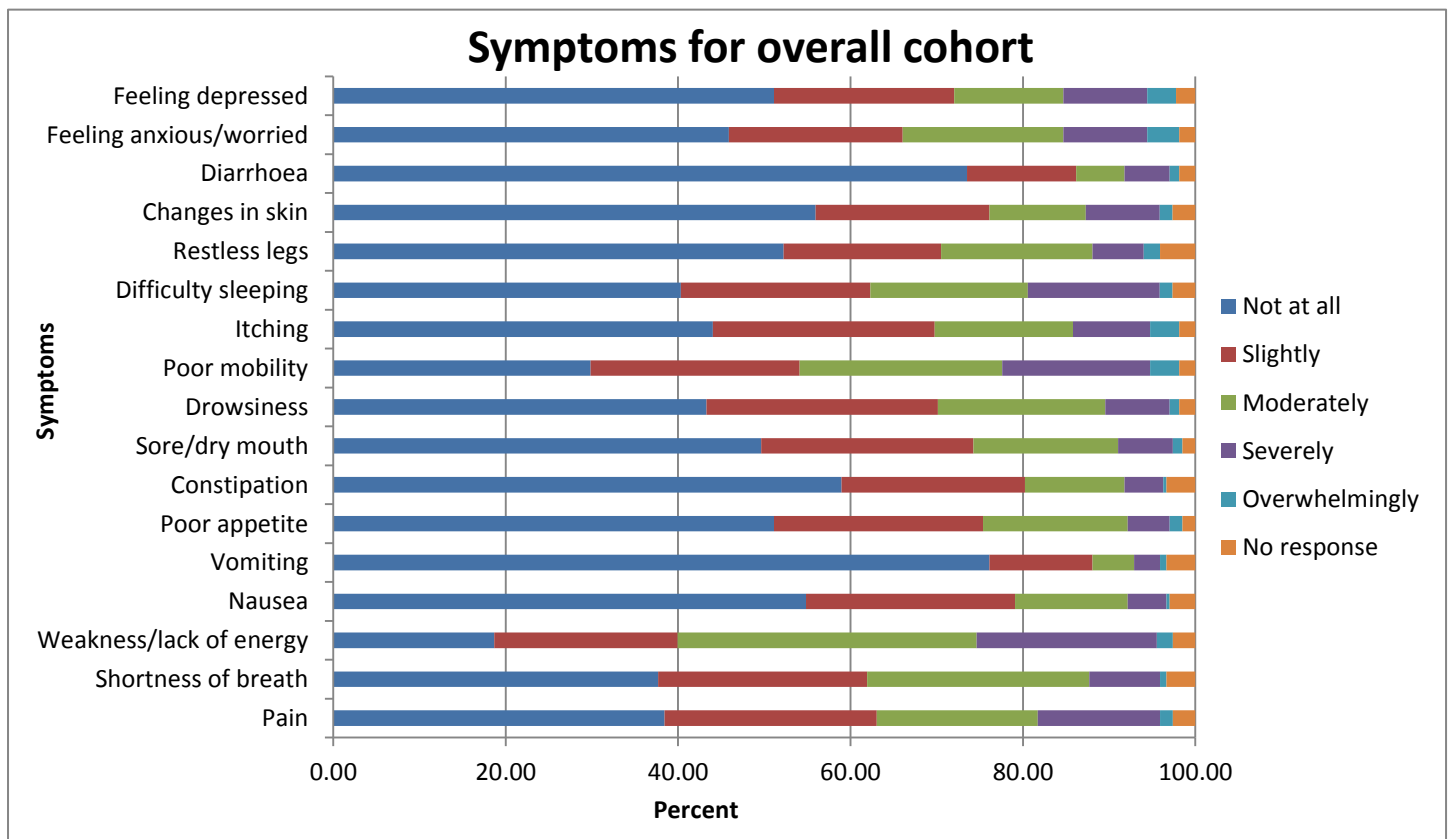


Figure 5 Symptoms for HD patients

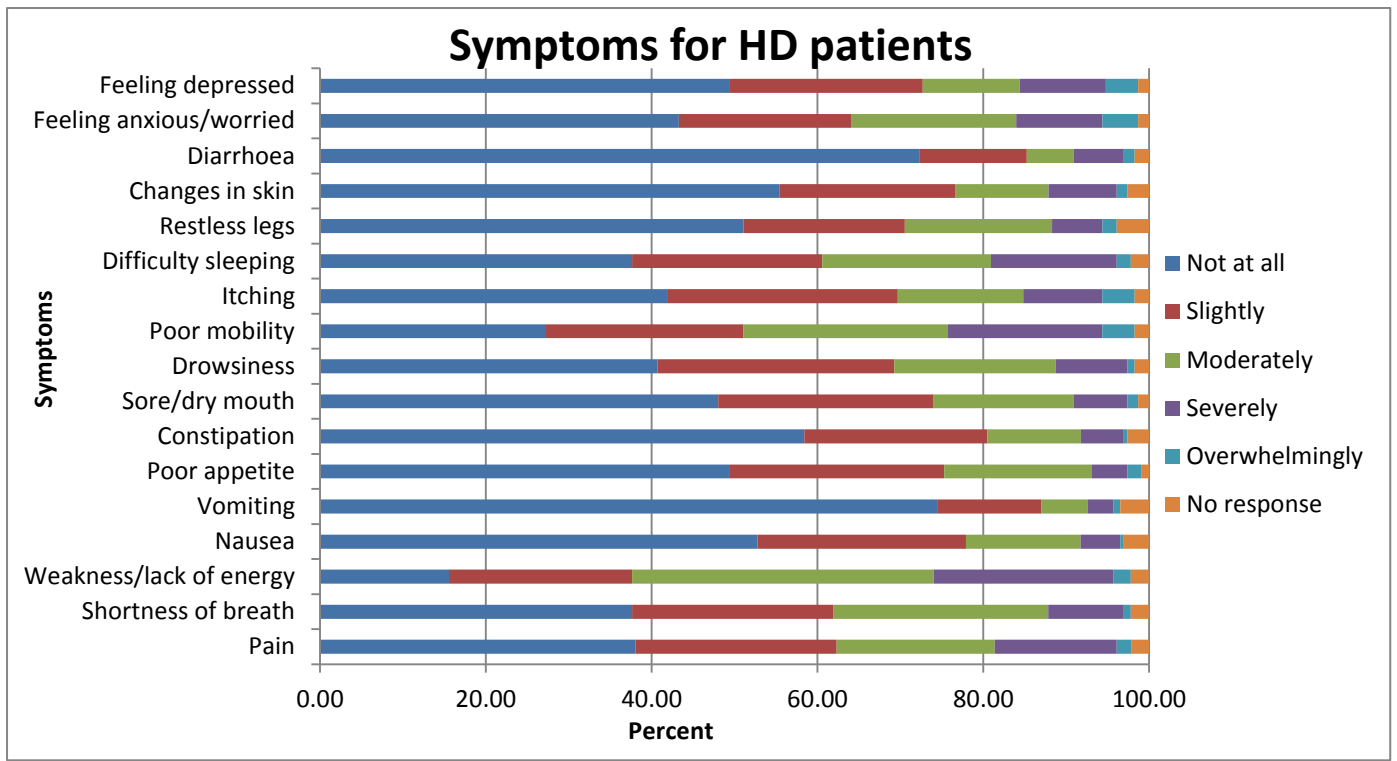


Figure 6 Symptoms for PD patients

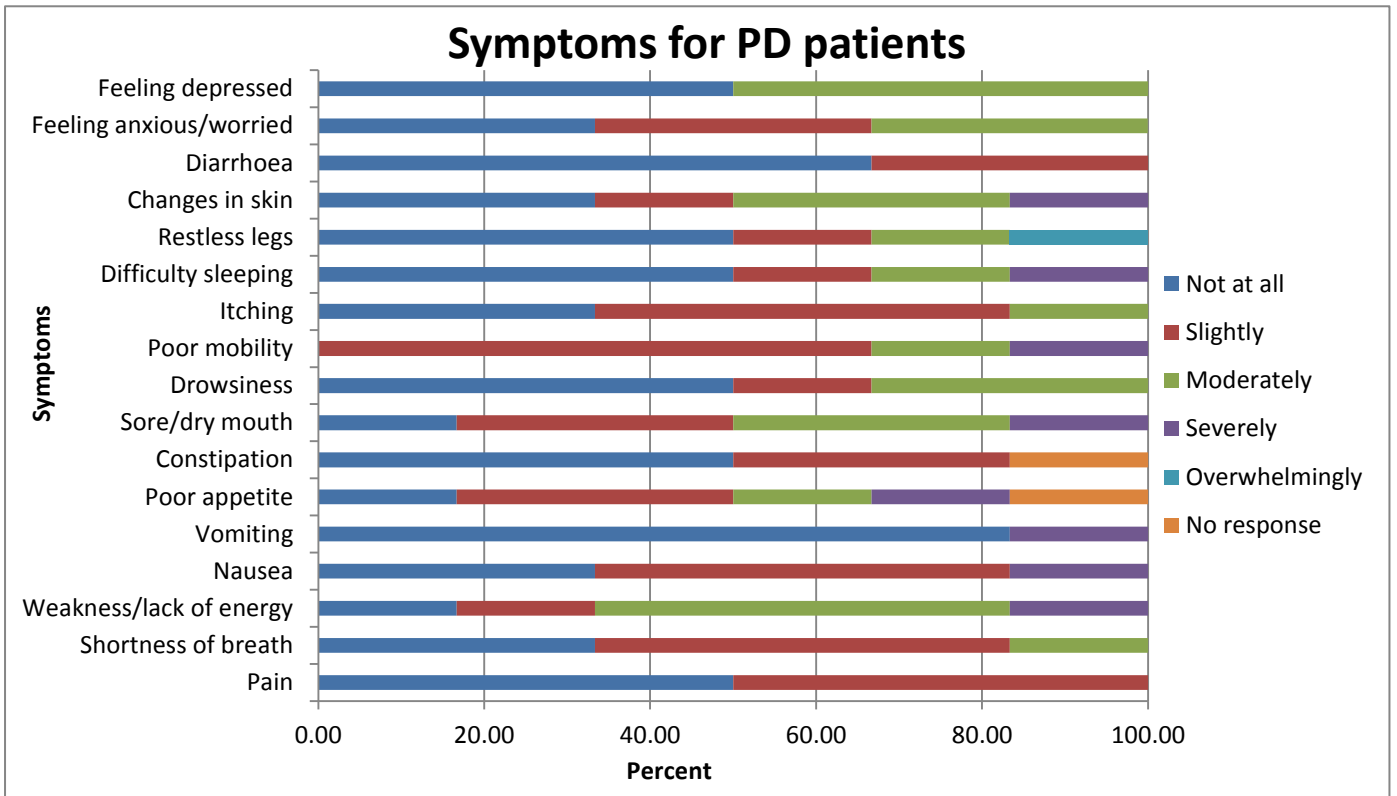
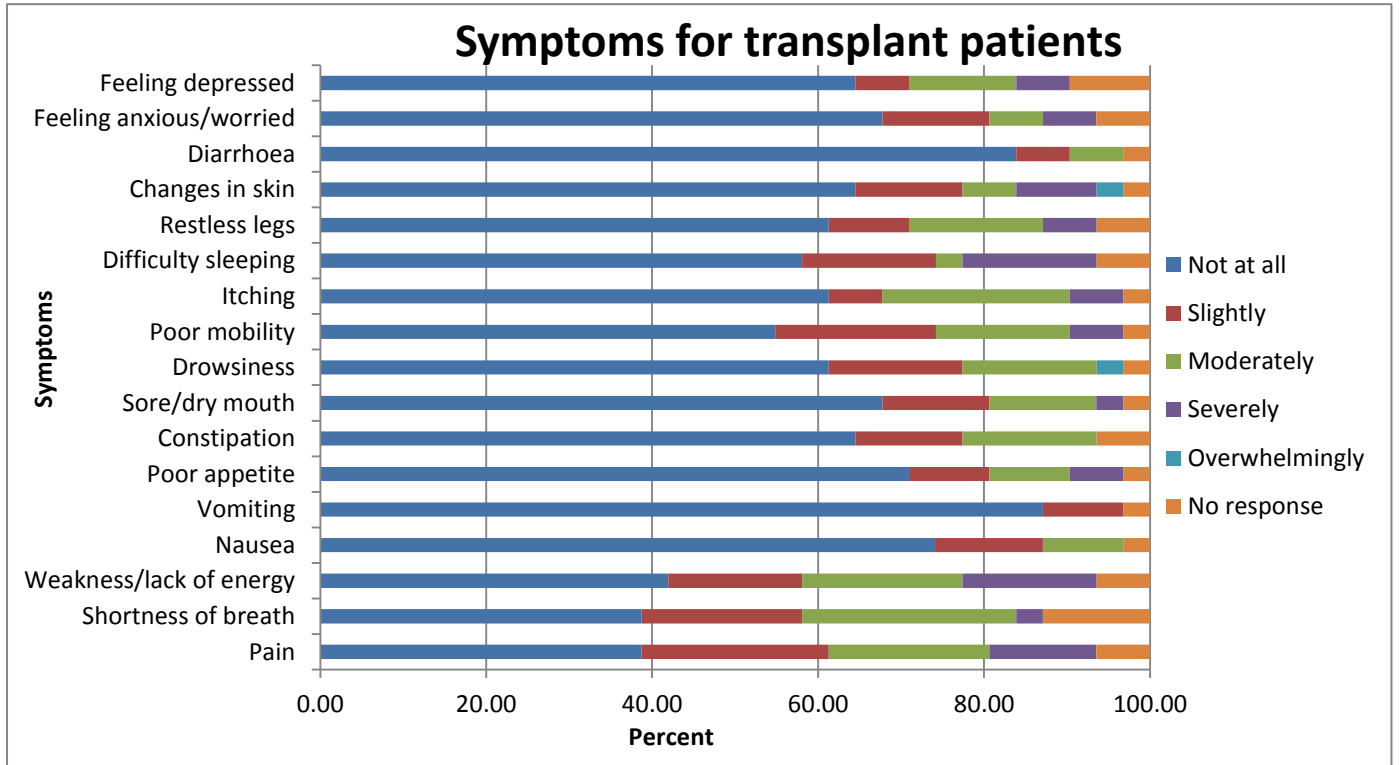


Figure 7 Symptoms for transplant patients



### Session 3: Haemodialysis Workshop

#### Who we met? Clinical teams from KCH's Haemodialysis units

The TP-CKD team ran a workshop with haemodialysis staff – some of whom had been involved with the TP-CKD programme, and others who had not. All of those who attended agreed that collecting this data was beneficial and that they would like to be involved in the programme. There was a particular interest in capturing the PAM/PROM results of new patients just beginning haemodialysis. Paula Maloney from Bromley Satellite unit attended, and staff were interested in using Paula's experience at Bromley to help with the implementation, as well as learn about using the data within MDMs and recording it using Renal Ware.

#### Looking Forward:

- Staff agreed to look at processes to support re-surveying
- Once staff have started implementation they would like a follow up to look at [interventions](#) especially around [Patient View](#) champions and nurses [writing letters to patients](#)

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## Session 4: Low Clearance, Transplant and Home Therapies Workshop

**Who we met?** *Clinical teams from KCH's Low Clearance, Transplant and Home Therapy units*

This was a very enthused group who were positive about implementing PAM/PROM across their PD cohort and in CKD /transplant clinics.

### Looking Forward:

- **Within PD patients:** Staff would like to try and implement the survey during the nurses clinic, then look at cohorting the patients with low activation levels (PAM level 1 and 2) and matching them with peer supporters
- **Within Transplant patients:** Staff would like to implement the surveys at patients' transplant anniversaries and then use this data within clinics
- **Within Low Clearance patients:** Staff would like to implement the survey at patients' first appointment with the nurse and at home visits. They are interested in the use of peer supporters *within* the clinics, and would like to offer patients with low activation levels (PAM level 1 and 2) peer support, which would be available in the out-patient department. Highly activated patients (PAM level 3 and 4) could also be recruited as peer supporters.

### In Conclusion

There was real evidence of strong leadership and support for person centred care from staff at King's College Hospital, and enthusiasm for spreading and embedding the collection of PAM and PROM across the patient pathway. The TP-CKD team felt this provided a real opportunity for shared learning with other renal units and hope to be able to capture the approaches used at King's as a positive example of Quality Improvement in progress. There are particular opportunities for sharing experiences in the use of Peer Support in implementing the TP-CKD programme, as well as KCH's use of their internal renal patient record system to support PAM/PROM data collection.

### King's College Hospital Peer Support Resources

- [Peer Support Handbook](#)
- [Peer Support Training Manual](#)
- [Patient-to-patient peer support in renal care - What why and how](#)
- [Peer support increasing participation through clinician engagement](#)

*Do you have any queries for King's College Hospital about their involvement with the TP-CKD Programme? Get in touch with TP-CKD leads Eleri Wood or Rob Elias on [eleri.wood@nhs.net](mailto:eleri.wood@nhs.net) or [robert.elias@nhs.net](mailto:robert.elias@nhs.net)*