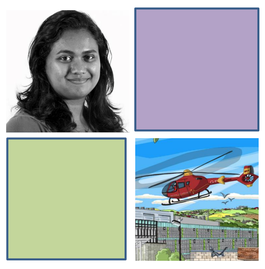
# TRANSPLANT FIRST: A TOOL FOR COLLECTING DATA ON WHY PATIENTS MISS TRANSPLANT LISTING AND LESSONS LEARNED FROM ACROSS A REGION



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**INTRODUCTION:** It is well recognised that there is inequality in access to transplantation across the UK. Our region had one of the lowest rates of pre-emptive transplant listing, and hence transplantation, and so in June 2015 we began a two year QI project to address this inequality (TRANSPLANT FIRST: ADDRESSING INEQUALITY OF ACCESS TO TRANSPLANTATION ACROSS THE WEST MIDLANDS). All seven renal units and two transplant units agreed to take part. We held a launch event involving multidisciplinary teams and patients. It was agreed to openly share data within the region and to collect information on why patients arrived at dialysis without a transplant status which could then be used to drive change. There were other elements of the project including work on patient pathways, guidelines, and information, which have not been described here

**METHODS:** NHS England's Quality Dashboards were already being collected nationally via the Renal Registry (RR). We therefore teamed up with the RR to produce an enhanced dashboard. For each patient who reached dialysis without a recorded transplant status, or who were potentially suitable but still in the workup process, units had to identify the cause from a number of defined options. A theoretical example is shown here. The data returns were reviewed by the clinical project lead who fed back to individual units and to the region as a whole

**RESULTS:** Units initially found it hard to collect this data. There is a natural tendency to look at each individual patient as an exception rather than look for systematic problems. Sometimes returns have included cut and pasted definitions which differ from the drop down list. Over the first three quarters of the project the proportion of patients who were being referred late for workup fell from 7/19 to 4/27.

Patterns of causes for missed listing can be identified, some of which are likely to be transferable to other units and others pointing to local issues which need addressing and can be used by the local project team to affect change.

Transferable causes:
- Failing transplants
- Predictable but rapidly declining patients
- Different approaches to cardiac angiography pre-dialysis

Local Causes:
- Specific clinics (e.g. diabetes multi-disciplinary)
- Different feeder hospitals

Barriers for using the data effectively include separation between those collecting the data and those engaging in the QI project.

There is evidence that access to transplant listing is improving in the West Midlands

**West Midlands Strategic Clinical Network** — ***Transplant FIRST***

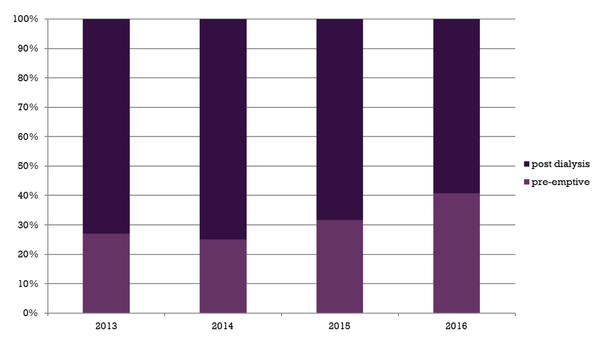
| | |
|---|---|
| **Renal Unit** | Stoke - North Midlands |
| **Contact Email** | |

List all patients who started Dialysis , HD or PD in quarter who fit inclusion criteria - ending 31/12/15 (nb total should be same as denominator for dashboard return)

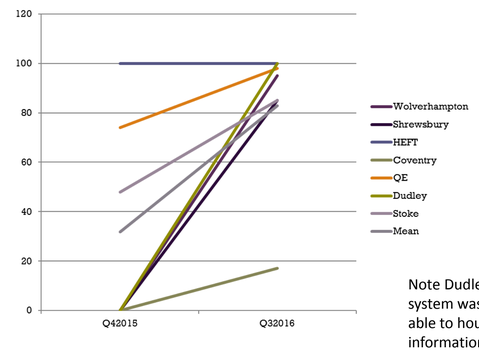
| ID no Renal unit use only (do not include hosp or NHS no) | Transplant status (choose one for each patient) | Reason patient still "working up or under discussion" or "no documented decision" (if you have chosen one of these catagories in previous column please choose category from drop down list) | Comment |
|---|---|---|---|
| 1 | Active on list | | |
| 2 | Suspended from list | | |
| 3 | Unsuitable | | |
| 4 | Working up or under discussion | Referred for Assessment when eGFR < 15 | |
| 5 | No documented decision | | |
| 6 | Unsuitable | | |
| 7 | Working up or under discussion | | |
| 8 | Unsuitable | | |
| 9 | Suspended from list | | |
| 13 | No documented decision | Unsuitable for transplant but NOT documented | |
| 14 | Working up or under discussion | Referred for Assessment when eGFR < 15 | |
| 15 | Working up or under discussion | Referred for assessment within 1 year of predicted date of reaching ESRF | |
| 16 | Working up or under discussion | Patient DNA on at least 3 separate assessment Appointments | |
| 17 | Working up or under discussion | Medically Complex | |
| 18 | Working up or under discussion | Delays in system | |

Must complete if 'Working up or under discussion' or 'No decision documented' in previous column - Transplant status

Proportion of patients pre-emptively listed at UHB




% of CKD 5 patients with recorded transplant status on Renal Unit IT system




Note Dudley's IT system was not able to house this information

**CONCLUSION:** In this project a large multidisciplinary team are striving to improve access to transplantation for patients in the West Midlands. We hope that by collecting this data we will track improvements. More importantly for the short term, the teams who are using this enthusiastically are finding it very helpful to promote change, either by individual feedback or identifying systematic delays. The process works best for units when the project leads are actively involved in reviewing their own data. In these cases they have been able to use the data to provide evidence for and promote change. However refining the collection tool has been surprisingly difficult. We are now going on to collect similar information on all patients at the point of transplant listing. We aim to have a finalised spreadsheet soon and the RR are developing a portal to collate and track the data. These resources will form part of the roll out of the project supported by KQUIP. Thus we hope that the teething problems we have gone through will ease the way for other regions adopting Transplant First QI and improving their patients access to transplantation.