South West Transplant First

Quality improvement leads meeting

13th December 2018 09.30 – 11.30

Introductions

Attendees:	Apologies :
Steve Dickinson - KQuIP SW lead	Lucy Smyth – Exeter
Rachel Gair– QI Programme Manager	Wai Tse - Plymouth
Catherine Stannard – QI Programme Manager	Imran Saif - Plymouth
Lynsey Webb - Exeter	Rob Parry - Truro
Heather Atkins - Exeter	Andy Demaine – Plymouth patient rep
Karen Steer - Exeter	Preetham Boddhana - KQuIP SW lead
Dennis O'Sullivan – Exeter patient rep	Neil Bebbington – Gloucester patient rep
Kwanruethai O'Sullivan – Exeter carer rep	Richard Powell - Plymouth
Jim Moriarty - Gloucester	Linda Boorer - Plymouth
Helen Giles - Gloucester	Lesley Read - Bristol
Dominic Taylor - Bristol	Deborah Duval – Truro patient rep
Samuel Turner - Bristol	Keith Bucknall – Plymouth patient rep
Leanne Savage - Plymouth	
Sue Durkin - Truro	
Emma Johns - Truro	

Data – case for change

Steve Dickinson refreshed attendees of the transplant data that was presented at the South West regional day and summarised the issues that it presented to the region

Click here to view the data and presentation

Group discussion – main issues to be addressed

Discussion was then opened out to the QI leads to raise issues they see as a priority and that they would want to see addressed as part of the Transplant First programme

The issues that arose are summarised below:

- There isn't at the moment standardisation of the cardiology work-up pathway regionally – what are essential evidence based investigations (stress test/CPET)?
- Having a uniform cardiac work-up agreed at the beginning of patient pathway would be valuable, and patients would/could be informed of this from the start
- Acceptance of deceased donor kidneys – potential to learn from Plymouth who use a voting app. during multi-professional meetings to aid in decision making and learn from past decisions
- Patient experience – transparency and better/ clearer information regarding criteria for suitability for transplant (particularly if denied – proper explanation required)
- Bristol unit had identified that they wish to reduce the number of visits to unit for live donors (7 at Bristol, would like to reduce to 2/3). It was acknowledged that a challenge to this may be changing consultant job plans. Also, they had considered setting a target of 100 days to complete donor work up
- Number of visits to unit for recipients (across both referring and transplant centre)
- Exeter explained that local nephrologist review of potential donors allows early sense check on the suitability of donors; without this transplanting centres would be seeing more patients who would be found to be unsuitable as potential donors
- Exeter; psychologist works 1 day a week, and waiting list is 3 months
- Gloucester were not confident that the NHSBT data for the unit was complete
- Plymouth have a standard of donors ready for transplant 10-12 weeks from first meeting (for uncomplicated donors)
- Patients in west Cornwall may prefer more local initial tests rather than multiple trips to Plymouth
- All agreed that capturing the patient experience of the pathway would be valuable

The NHS change model

Rachel Gair gave a presentation on the NHS change model which is being used as the framework for KQuIP

View the NHS change model presentation here

There was then a discussion on refining the 'Shared Purpose' of the Transplant First South West programme building on the previous discussion.

Initial thoughts are summarised below:

Aim:

"As many people transplanted in as little time as possible"

'' Reasons to transplant – not reasons not to''

We agreed that the following objectives would be good standards to work towards in the SW:

- A maximum of 18 weeks pathway from initial appointment to transplant for both recipient and live donors (cross-centre – following *patient* rather than centre)
- Maximum of 2/3 visits for non-complex live donors and recipients before operation
- % pre-emptive listings – mirroring the Transplant First objective of 'half of all patients on the transplant list to be pre-emptive'

Drivers:

- Time from referral to ready for transplant/ activation of the waiting list for recipients (discussion that from the patient perspective the 'clock starts' at the time of initial work up, and recognition that this is possibly more difficult to capture if the transplant centres are measuring, rather than the referring units)
- Time from initial appointment to nephrectomy for live donors
- Number of visits to units (referral and transplant) for both donor and recipient
- Standardised cardiology work-up pathway
- Communication between referral and transplant centres as soon as patients are on the work-up list - on work-up pathway, time of listing, preferable site for pre-treatment etc

Measures

- Patient experience- both recipients and donors (and people who had donor work up but were ultimately not able to donate)
- Days from initial referral to listing/ operation for recipient and donor
- Number of visits to centres throughout pathway (we debated whether donor work up should be a 1 stop shop or is this too rapid in which to make decisions for some patients)
- Number and proportion of patients who receive a pre-emptive transplant

The KQuIP offer

Catherine Stannard gave a presentation outlining the support available from KQuIP and the KQuIP programme framework.

View the KQuIP presentation here

The commitment to the framework and timescales of the programme proposed were agreed, with the launch of the programme being April 2019 and celebration event in April 2020.

The next gathering for the South West QI leads will be on 6-7th February for the residential leadership training – this is likely to be held in Taunton.

- **Working together**

It was agreed that Catherine and Rachel would investigate Yammer – an online forum for organisations where you can post messages/information/resources/documents and generally keep in touch. This will avoid lengthy email trails!

Potential for including a cardiologist within the regional group

All agreed that patients should be included from inception

Summing up and actions

To assist in the planning and preparation of the Transplant First South West programme, between now and the next training work-shop (early March), unit QI leads were asked to prepare the following information to share at the next meeting:

- Process map their cardiology work-up both for recipients and donors
- Collect data and bring to the next meeting information on the Number of transplants done in last 11 months (April 2018 – March 2019) from each unit inc.
  - How many pre-emptive
  - Deceased/ live etc
- 3-5 real-life case studies of patient journeys (donors or recipients).
  - These can be positive or negative examples
  - Including pathway timelines
  - Ensure PID is not compromised

Catherine, Rachel and Steve agreed to:

- Investigate how patient experience was measured by Teeside during their programme
- Get in touch with Belfast renal centre – potentially invite to upcoming meeting
- Ask for Kerry Tomlinson's 'example letter' to other specialities who slow listings down
- Set up Yammer and share with the group
- Circulate PHNT new pathways

- Investigate whether the new NHSBT allocation policy has been finalised/ is active
- Explore whether there is a Cardiologist with national expertise in kidney transplant (recipient and donor) work up, and if so invite them to the launch meeting and/or future meeting
- Circulate dates for follow up meetings and launch event

Thank you for your enthusiasm and time and Merry Christmas