Launch Event
South West Team Transplant
SW KQuIP
11th April 2019

Introductions and welcome

Paul Cockwell KQuIP co-chair gave a brief overview of the importance of KQuIP in progressing regional networks, supporting GIRFT and aligning with the 10 year NHS plan.

Steve Dickinson the regional lead welcomed the QI leads and patient leads from the six units in the SW region as well as other members of the multi professional team who had been invited.

Current Transplantation Activity in the South West and the national picture

Steve Dickinson gave a brief outline of

- How did we get here?
- National and SW regional level data Where are we now?
- How will we achieve the agreed aim by means of the following drivers – supporting communities, education for all and reducing delays?

He also explained the advent of South West Team Transplant (SWTT) and the importance of owning the project within our region.

Transplant First in the South West

Each of the six SW units presented slides on a topic that was pertinent to them as a unit but also impacted the agreed overall aim

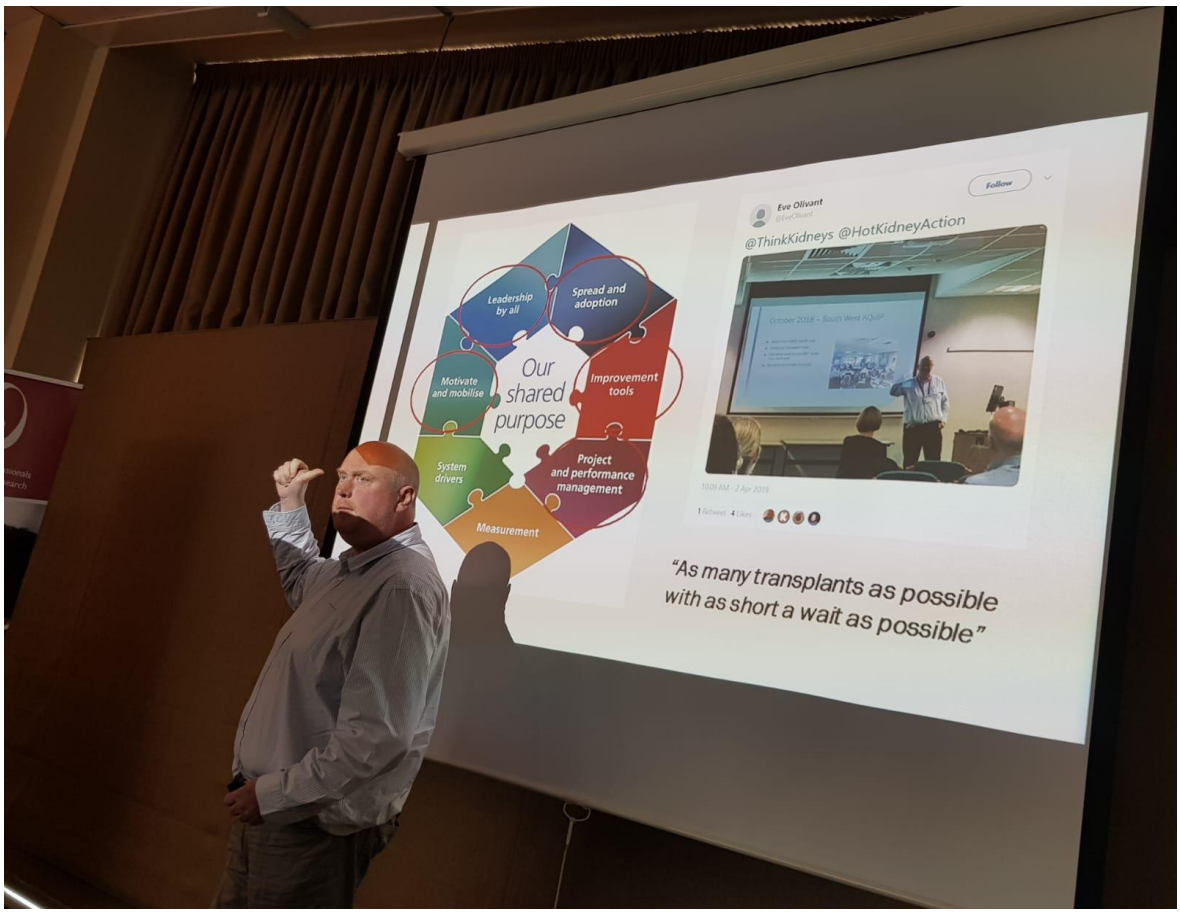
Overall AIM – SW Team Transplant

'As many people transplanted with as short a wait as possible with the best experience'

Drivers:

- Supporting communities
- Education and awareness for all
- Reducing delays

RDE: Barriers and delays in renal transplant work up and living kidney donation …how to resolve them
Dorset: The Donor Process
Gloucester: Wait times and organ turn down rate
PHNT: Living Donor Pathway & Activation onto Transplant Waiting List Pathway
NBT: LKD pathway and Transplant referral proforma
RCHT: Donor Experience



Patient Experience

Keith Bucknall spoke about his experience of entering into a potential live donor transplant from his son in law – the emotion and awkwardness associated with talking about it openly without feeling that either was coercive. The lack of understanding of where either one was along the pathway or how much longer they might have was emotional and at times difficult to address with one another, but also the transplant team.

Deborah Duval discussed the need for patient education that was consistent, clear and timely. She showed an example of Guys and St Thomas' which as a patient felt was exemplary in that it addressed the whole of a patient's journey.

World Café Session

Delegates were invited to attend each table in any order and discuss the following topics within a 7 minute timed session.

Table 1: Kerry Tomlinson – Measurement - What shall we measure and How?
Table 2: Keith Bucknall & Deborah Duval - Patient Experience – how to measure and improve
Table 3: Steve Dickinson - Objectives – Do we have any targets? If so, what are they? Are they South West targets or unit targets?
Table 4: Jim Moriarty - How do we raise the profile of South West Team Transplant locally and regionally?

What shall we measure and How?

- Length of pathway from referral to donation
- % suspended on list and time frames
- LD rates
- Pre-emptive listing rates and pre-emptive transplant rates
- Staff experience measure – feedback on project
- % patients that have 'suitable for Tx' made at a given eGFR (?<20 or 30)
- Patient experience – donor/recipient
- eGFR at referral to TAC
- PROM – QOL, survival etc
- Compliance with referral pathway – does this impact waiting times
- IT systems

Patient Experience – How to measure and improve it

- Education – who drives the information?
- Information on drugs and affects of them – choice
- Getting people back into life style and daily life
- What is the benchmark for patient experience?
- Develop recipient and donor networks for ongoing support
- Follow up of Donor after transplant
- Decision making is key to a good experience
- Capture stories and honest opinions
- Importance of patient peer support
- Use and promote KPA's
- Renal teams have to measure patient experience as it informs future care
- Need further involvement of AHP such as social workers, psychologist, chaplains

How do we raise profile of SWTT locally and regionally?

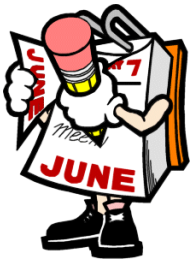
- Do a KPA local talk eg AGM
- Talk at trust Grand round medical mtg
- Internal comms- weekly Trust bulletin
- Add KQuIP as a standing agenda item on renal business meetings
- Twitter account for SW Team Transplant
- Write some papers/ publications on our work
- Discussed tx games, tx week Newport. Newcastle

Should we have regional/unit targets – if so what are they?

- SMART – 20 by 20 pmp
- Every patient at eGFR has documented status
- Talk Transplant at eGFR 25
- Agree target for when clock starts – return of NBT proforma/first discussion with professional?
- Theatre space – use every available session
- Targets for pre-emptive rates
- Targets for listing pre-emptively requires more data
- Agree uniform referral from – NBT/SWTC
- Agree 18 week pathway regionally – referral to readiness (moment of decision) or referral to TAC as start point
- Monitor how referrals come in – what has been done already
- Current staffing levels – Tx specialist nurses and admin support
- Resistance to setting pmp deceased/live donor rates
- Listing as suitable – use SWTC experience of improvement
- Cold ischaemic times – set a target

Implementing change – barriers and how to overcome them

Transplant First project lead Kerry Tomlinson shared her experiences of implementing Transplant First within her region.



A brief summing up was given by Rachel Gair outlining further dates in the diary and follow up communications. Rachel and Catherine offered to visit units if it would be helpful.

Dates for diary:

Training Day 1 – 11th June (all day event)

Training Day 2 – 24th September (all day event)

Training day 3 – TBA December 2019

After lunch all QI leads including patients stayed behind for a sharing and learning round table discussion. Steve Dickinson led the discussions drawing on the issues raised from the world café session before lunch. These are as follows:

Measures and targets – discussion points

"More transplants, faster" as the aim?

- One of the common themes from the morning sessions regarding patient experience was about 'waiting, waiting and more waiting'
- It was concluded that there was an 18 week pathway for donors/recipients already which seemed to end with a surgical clinic but no-one was really sure what it looked like or whether their Trusts are using it
- NBT looking to expand theatre time by 1 session a week to perform live kidney transplants- so this could potentially lead to a change from 29 a year to 40-50 (an increase potentially from 8pmp to 10pmp)
- Plymouth are already reviewing their patients as suitable for transplant with an eGFR < 20
- ATTOM also showed virtual CKD clinic check helps
- Gloucester challenged Bristol- over cautious and turning down kidneys?
- Dorset- many of the patients cardiology test are done at other hospitals. Dorset also refer for Tx to Portsmouth.
- Dorset have a hospital policy that the GP should refer back to Dorset unit for ongoing Tx work up which has the potential to cause delays. Paul explained that if this is delaying activity then kquip/rr could write to the Trust to suggest a rethink on this policy.
- Dorset have 1.4wte spec nurses for all donors and recipients which seems insufficient - GIRFT can inform staffing numbers
- Truro discussed Kidney failure risk equation- little interest shown from other units at this stage.
- Exeter have different t typing instructions from Bristol and Plymouth
- All units agreed difficulties getting blood groups done- no quick solutions suggested.
- Does rapid work up mean in some cases unnecessary work up?
- Bristol have created a standard referral form. All agreed it was a good idea but needed to be done consistently throughout the region. All colleagues need to be involved in the creation to ensure this as Imran explained similar in Plymouth had not had good sign up. Bristol agreed to circulate the proforma internally asking for comments and then do a test cycle at NBT before developing further across region.
- Plymouth are going to be early adopters (ie this yr) of the tx tariff.
- Plymouth's recipient pathway for 1 day medical review can cater for 2 patients on the day (ie 2 patients a week)

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Communication of SWTT

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Patient Experience

- Plymouth (Linda) has trained 6 or so renal patients through PHNT Trust volunteer service who are also hospital volunteers and act as expert patients/ link patients
- "Donor Family Network" was mentioned as a potential support mechanism
- Rachel and Kerry are working on Patient and Donor Experience measure which can be piloted in SW
- NHSBT are working on DROMS
- Kerry is running a Tx first webinar 2 May, illustrating the online data tool which she also demonstrated
- Kerry explained:
  - A lot of time and effort invested in patient info leaflets, but to no avail
  - Patients mobile numbers were added to the letters to the referral centres
  - Kerry warned against explaining away patients missed from the egfr<20 activity
- Recipients keen on more info on their listing
- A kidney donor can expect to be off work for 6 weeks afterwards which at times isn't clear from the start
- Objective questionnaire required at transplant and after a year to gain full experience

Unit work before the next meeting

1. Discuss your local strategy that will allow you to measure how many of your patients with an egfr<20 (or anticipated to reach esrf within 12 months) have had a documented discussion (aka decision) reached about transplantation.
2. Present how many patients (donors and recipients) have started the 18 week clock since 1 May
3. Discuss one aspect of involving patients you have started to do (or are planning to do differently)
4. Discuss one method that they have done or are planning to do, to raise profile of South West Team Transplant and its aims etc.