NHS BLOOD AND TRANSPLANT
ORGAN DONATION & TRANSPLANTATION DIRECTORATE

MINUTES OF THE TWENTIETH MEETING OF THE KIDNEY PATIENT GROUP HELD ON THURSDAY 16th JULY 2020 VIA MICROSOFT TEAMS

PRESENT:

Rommel Ravanan	Chair of NHSBT Kidney Advisory Group – **Co-Chair**
David Marshall	**Co-Chair:** Kidney Patient Group
Lisa Burnapp	Lead Nurse for Living Donation, NHSBT
Andrea Brown	National Kidney Federation
Nick Flint	Queen Elizabeth Hospital Kidney Patients' Association
Jim Higgins	National Kidney Federation
Tess Harris	Polycystic Disease Charity
Fiona Loud	Kidney Care UK (from 11.30am)
Kirit Modi	National Kidney Federation
Tracey Murray	Kidney Research UK
Paula Ormandy	British Renal Society, Kidney Patient Involvement Network (KPIN)
Kathleen Preston	Lay Member (Leaving at 1.20pm)
Matthew Robb	Statistics & Clinical Studies, NHSBT
Adnan Sharif	NBTA Representative
Samantha Sharp	Kidney Care UK (until 11.30am)
Retha Steenkamp	Head of Operations, UK Renal Registry
Bruce Willan	Deputy for Charlotte Silver, Corporate Communications, NHSBT
Robert Wiggins	Give a Kidney Charity

In Attendance:

Trudy Monday	Clinical & Support Services, OTDT (NHSBT)

ACTION

Apologies:
Chris Callaghan, National Lead for Organ Utilisation (Abdominal)
David Coyle, Kidney Patient Involvement Network
John Forsythe, Medical Director, NHSBT
Andy Henwood, Kidney Patient Involvement Network (KPIN)
Helen Lewis, Independent Researcher
Julia Mackisack, Lay Member
Maggie Pratt-Heaton, Six Counties Patients' Association
Rob Ryckborst, Kidney Patient Association, West Midlands
Jan Shorrock, Give a Kidney
Charlotte Silver, Corporate Communications - Senior Communications Officer, NHSBT
Douglas Twenefour, Diabetes UK

1 Welcome and Introduction

Everyone was welcomed and thanked for joining the meeting. It was announced that this meeting was being recorded for the purpose of the minutes only. 'Housekeeping' points were communicated to all, and feedback invited re. the using of Microsoft Teams for this meeting.

2 Approval of minutes from previous meeting – KPG(M)(19)1 and Action Points KPG(AP)(20)1

The previous minutes were agreed as a true and correct record.

To be ratified

ACTION

Action points were discussed as follows:

AP4: Development of a BAME strategy on organ donation: post 2020:
K Modi reported that the Kidney Advisory Group (KAG) were asked to consider access to transplant for those patients from BAME and low socioeconomic groups. In light of COVID-19 it is now a major issue. There does not seem to be a view communicated by the KAG on this matter, and so it was asked for this to be reconsidered by the KAG in light of the COVID experience. R Ravanan agreed to have an offline conversation with K Modi regarding this. **R Ravanan / K Modi**

AP5: Collaborative working on the National UK Kidney Sharing Scheme:
L Burnapp confirmed that this relates to a discussion around the willingness of recipients and donors to move centres for transplants. This has been taken forward already: there is a fixed term working group in progress (which is on hold currently due to COVID-19), a donor survey has been conducted, and an ongoing collaborative between the London and Northern regions. L Burnapp agreed to provide a report from the fixed term working group for the next meeting in 2021. **L Burnapp**

AP8: M Robb reported that this was discussed a couple of months ago and due to COVID it will not happen in the immediate future, but he will look to attend a meeting in the time to come. R Steenkamp will be sending an invitation to M Robb. **This action is now closed for this meeting.** **R Steenkamp**

3 Medical Director's Report

R Ravanan reported on behalf of J Forsythe – as he is on annual leave and sends his apologies.

Report on work of ODT and KAG in the last 4 months: Since early March, the advisory group Chairs and operational leaders in ODT have met virtually twice per week. This senior team has been working through the risks with all clinical teams within transplant centres for all organs in terms of preparation for the pandemic. Since last week these meetings have reduced to once per week. During these meetings some major policy decisions were undertaken.

Summary of key points from the donation side:

- Intensive care units were thought to be under significant pressure, expected that organ donation would struggle because of ITU needing to prioritise their resources for COVID patients, and organ donation numbers decreased.
- Some organ acceptance criteria was changed (eg: age of donors). It was stepped down in March to June, and is now resuming to normal age. It has also been considered as to what would be a 'safe' organ donor, and would it be safe for example, for a patient in ITU with lots of COVID patients to be an organ donor. Best medical advice was used to form a policy to define safety of organ donation during the pandemic.
- Safety of the NORS teams – team members would normally share transport, so there was a necessity to ensure that those clinical teams remained safe. In March/April there were concerns around availability of PPE.
- Kidney Transplant activity declined significantly from March – there have been three main reasons: 1) Kidney transplant doctors, surgeons and nurses had to be prioritised into other clinical settings based on need. 2) Hospitals had to prioritise resources including ITU capacity, anaesthetists, theatres etc. 3) Finally, an unknown element: clinicians were unsure if weakening the immune system for transplant patients during a pandemic was appropriate. There was a requirement to collate data quickly, quantifying the risk, communicating that to clinicians and patients to enable informed decisions to be made.
- The hospitals in the West Midlands and London at the start of the pandemic

To be ratified

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(beginning of March/April) had a challenging time; the south west, NI, Scotland etc did not experience the same in comparison. Weekly clinical team meetings had to respond to these issues, reviewing policy, arriving at a consensus, making kidney transplant updates available on the website, communicating with clinical teams etc.

- Centres had to suspend their programmes. From late March/early April, three units remained open throughout: Oxford, Cambridge and Newcastle. The full waiting list was not active so clinical decisions had to be made with their patients. Mid-April onwards, centres which had suspended programmes started to come back online. Glasgow and Belfast reopened first. By mid-end of May about half of the kidney centres reopened. *Post-meeting note:* As from 20th July, of 23 adult kidney transplant units there were only 5 units not fully open; the expectation is that these will be open by the end of July with one centre likely to a bit longer.
- Out of the 7 paediatric units, Birmingham stayed open for a couple of urgent patients; all other units closed. They have since been reopening, and by the end of next month all units should be open again. Jan Dudley, the Paediatric Lead for the sub-group, has been leading on this.

Questions:
On behalf of the National Kidney Federation (NKF) K Modi expressed grateful thanks to NHSBT and the transplant community for the care given to patients and the personal risk in doing so. It has been fully recognised that transplantation will take time to revert to 'normal' and that there are issues of assessing risk and benefits on an individual basis, to which end the British Transplant Society has been producing guidance, possibly aimed at clinicians. The NKF ask if it is possible to work with NHSBT to produce a version of this guidance to be made available in a public language.
Secondly, it was asked if kidney transplantation for a dialysis patient should be considered in the same way in that chemotherapy is considered for cancer patients in terms of assessing risk with patients? L Burnapp confirmed that the BTS are very aware of these concerns, and a number of documents are being produced and then revised. There is very active ongoing work in progress looking at a risk matrix exploring different patient factors (recipient, donor, environmental, geographical, etc) to support clinicians and patients in having those conversations. On the Renal Association side, there are patient representatives on that group and this work will feed into this group. K Modi reported that the NKF would be very pleased to be involved in that work before it is published.

Summary of key points from living kidney transplantation activity:

- For a variety of reasons, partly related to resource, partly related to the fact that clinical teams have been working outside of their normal specialties, and concern that the healthy donor may contract COVID, have all caused a significant slow down in LKD activity.
- Across the UK, all adult and paediatric living donor activity ceased in March and most of April. During May and June living kidney programmes started recovery – this was proving difficult in that those patients were then competing with other patients who needed urgent surgery. In most hospitals clinical activity was not as productive for a number of valid reasons including testing of all patients to ensure everything was safe and additional PPE required, so there was not such a quick turnaround for operating; ITUs were still full, and competing against other opposing priorities in hospitals.
- In mid-May the Royal College of Surgeons produced guidance for clinicians on how to prioritise patients in terms of the surgery required but 'transplantation' was not included at this time (an oversight). At the end of May, NHS England highlighted that solid organ transplantation should start again, and that it should be considered just as important. J Forsythe and the clinical teams worked hard

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with the Royal College of Surgeons to create guidance to reinstate transplantation activity – this guidance was communicated mid-June; centres have since reopened. NHSBT and NHS Commissioners from across the UK have been working to recover LKD programs.

- Shielding: NHSBT and clinicians were not involved in development of shielding guidance or comms strategy for transplant patients – this has been managed centrally by the Government. It is recognised that there has been a lot of confusion and it is still uncertain as to who is providing the guidance. L Burnapp reported that the Renal Association together with input from the BTS are looking at creating pragmatic guidance linked to the risk assessment; units have also been liaised with in order to come up with sensible ad helpful advice, trying to ensure people can continue with their lives as best as possible, with children going to school, etc.

4 COVID-19 Update
Transplant & WL group
Dialysis group

M Robb and R Steenkamp gave presentations on COVID in non-transplant and transplanted kidney patients with COVID specific outcome measures.

M Robb presentation:
Key points:

- First transplant centres closed on 14th March – only 3 transplant centres were left open by mid-April. At that point, the kidney offering was switched for those patients outside of tier A to go to local centre offering. On 10th June centres started to reopen; as of 16th June, reverted back to the full offering scheme.
- At the moment, figures suggest that there are approximately one third of patients active compared to February.
- During the last couple of weeks since the move back to the full offering scheme, the activity is what we would have expected pre-COVID.
- Mid-March living donor kidney transplantation completely stopped; numbers increased in May/June (at least 15 have been performed since May, but this information is not available to share yet).
- Outcome data has looked at COVID-19 positive patients on the transplant list, and kidney patients who have received a transplant. At 1st February 2020, 4789 patients active on the kidney transplant list, 193 (4%) have tested positive for COVID-19, and of the patients testing positive, 7 have died (0.15% of the list).
- Outcomes – transplanted patients: at 1st February 2020, there were 39,097 patients with a functioning kidney graft in the UK. Of these, 564 (1.4%) have tested positive for COVID-19, and of the patients testing positive, 155 have died (0.4%).
- Demographics: for those transplanted patients who tested positive, the highest number of tests by ethnicity were those in the white group, and the highest percentage of those tested positive and died were from Asian and black groups.
- Breakdown by age: highest number of those who tested positive were in the older age groups, and a higher rate of death from those who have had a positive test.
- NHS Region: a lot of variation with positive tests across the country: highest numbers were in London; there has been a variation in death rates across the regions.

R Steenkamp presentation: (Renal Registry)
As well as transplant patients, the Renal Registry collects data on those who receive haemodialysis and peritoneal dialysis; there is a limited dataset of chronic kidney disease (CKD) patients, and those have not yet started renal replacement therapy.

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- In-centre HD patients: this accumulative report spans the beginning of March when the first case was reported, to the end of May. There is a steep increase in the curve looking at in-centre HD; in early April the curve shows that the rate slows. Home therapy patient numbers have been quite low and constant. In the last week there were 8 new cases reported in the whole of England: one CKD, 6 in-centre HD, and one transplant patient. The number of cases are definitely slowing down.
- Data comparison between in-centre HD patients and HD patients: median age was similar; ethnicity breakdown: slightly more Asian and black patients who were COVID-19 positive; gender: similar; deprivation: more deprived areas have more cases.
- How these factors impact on survival, effect on outcome: older age groups have a much higher risk of death; ethnicity: higher proportion of deaths in Asian and black populations; gender: more males dying than females. Biggest risk factor is age. Gender is not statistically significant. Ethnicity: previous data showed the Asian community had a slightly higher death rate, but the accumulative data now does not show a significant difference in terms of outcome between ethnic groups.
- New cases by region: steep increase for R rate for London: reached its peak before other regions. West Midlands were the second highest, and North West third highest.
- Reproduction (R) rate: in March this figure starts at just under 3%, and dips to just under 1% during May – the figures are mainly driven by what is happening in London.

Questions:

Q1: P Ormandy: Question to M Robb: Is NHSBT going to look at comorbid conditions in transplant patients who have had their transplant for over 12 months and whether their kidney function at the time has been influenced from COVID-19?
M Robb: NHSBT do not routinely collect comorbidity information. In terms of factors that do affect outcomes a multi-variable analysis will be performed to identify factors that affect outcomes which will take into account for eg. the primary disease, and those factors which the summary data reports on so far (this work is ongoing).

Q2: P Ormandy: Question to R Steenkamp: Was there any difference in practice across centres that influenced the outcomes of the patients (and this should be included in patient guidance for the future)?
R Steenkamp: There was definitely differences in practice across the centres; the RR are collating that data currently to try to understand what happened in different renal units when considering the outcome of the patients. There is also a study being conducted in London at the moment looking at practice changes which have helped save lives for patients – that study will help re. practice if there is a second spike.

Q3: K Modi: Many thanks to M Robb and R Steenkamp for the presentations; thank you also to D Marshall and R Ravanan for agreeing to include these presentations. There is a close connection between the transplant and dialysis patients, so it would be of benefit to include information from the RR at these meetings going forward.

In terms of assessing risks and benefits, full account needs to be taken of these data. When this information is shared it can then be personalised to the individual recipient or donor.
M Robb: Analyses are being worked on looking at the risk factors associated with outcomes which will be shared in due course. With data, it is important to remember that mortality rates will be somewhat inflated as wide testing was not in place in the early stages of the pandemic, so with cases where there is a positive

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test these are the cases where patients would have been hospitalised.

Q4: K Modi: The National Kidney Federation (NKF) have been campaigning for many years for home dialysis – how can home dialysis be made available for more kidney patients to help avoid travel to hospital and therefore helping to keep them 'COVID safe'? The number of dialysis patients have increased for one unit (Luton) during the COVID period – has there been an increase nationally on the number of patients who are dialysing?
R Steenkamp: This data is not known definitively. It is possible that COVID could have affected those CKD patients who were dialysing in units. It is something which would need quantifying as it has implications for dialysis units and transplantation demands.

Q5: F Loud: There has been a high level of acute kidney injury: how will that data be collected re. the number of patients which have come through to dialysis via that route?
R Steenkamp: When the data is collated for quarter 1 and 2 it will show how many new starters there have been. This includes data from laboratories: every alert that has happened in England (AKI alerts and alerts for new starters of RRT).

5 Living Donor Kidney Transplant update: L Burnapp
Highlights from the LDKT 2020 Strategy: LDKT in the COVID era: The Future:

- Objective to achieve by March 2020 was quite a challenge: 26 per million population (a stretch target) has not been achieved. There is variation across the UK which needs to be addressed.
- Strategy Implementation Group has now disbanded (February). It involved extremely committed individuals (clinicians, and some from this patient group), led by Aisling Courtney. L Burnapp expressed grateful thanks to that group. In terms of what it had delivered, main achievements: integration of living and deceased donation in the next strategy; development of the UK Living Kidney Sharing Scheme; establishing the UK Living Kidney Donation Network; centre specific data and reporting; public and patient engagement; donor safety and outcome.
- In some areas of the strategy numbers improved significantly, and in particular those that contributed to the kidney sharing scheme. Enormous reduction in the number of incompatible transplants.
- Kidney sharing scheme has become the largest scheme in Europe. A lot of interest has been shown in the programme from other countries. The scheme has facilitated more transplants for both adults and children who are difficult to match.
- Non-directed donors: first time in 5 years there has been more than 100 donors; 50 transplants more from donors donating into a chain as part of the kidney sharing scheme.
- Recipient ethnicity: this scheme benefits those patients enormously; a majority of donors come from a white background.

Two initiatives:

- Final report of the National Transplant Initiative: NBTA were commissioned to contribute to this, raising the profile and the number of transplants from black and Asian people; has also extended to those from low socio-economic backgrounds. Final report indicated that some interventions do work, some are more effective than others. The report has provided the opportunity of being able to look at interventions targeted at specific groups with specific issues.
- Proceedings of the 2nd Workshop for the Network of National Focal Points on Transplant-Related Crimes: This is part of a wider group across Europe designed to protect donors from around the world re. exploitation. NHSBT is the national

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focal point for the UK to protect donors including those travelling from overseas.

What needs to be taken forward in the next strategy:

- There is a lot of variation in numbers of living donor transplants when comparing Northern Ireland with the rest of the UK – important for patients to get the transplant that they want and need at the right time.
- Impact of COVID-19: all LDKT activity paused in every centre; clinical teams redeployed; all project work paused.
- Since 28th May, achieved 21 living donor transplants; normal average is 80-90 per month.
- Restoration project to support re-establishment of clinical teams:
  There has been a reopening of centres week by week. A newsletter is due to be circulated this week to colleagues in the network. Some projects remain paused; some which are not achievable have ceased. Every centre has been asked to produce a restoration plan by 24th July (backed by commissioners across the UK): centres are asked to identify all outstanding transplants (the intention is to work out the feasibility of the October matching run, and avoid adding to it any outstanding transplants). Included in these plans will be a contingency plan in the event of a second surge: the aim is to avoid the complete closing of centres again.
- UK-wide market research survey was open for 2 weeks to assess the appetite for living donation in the COVID era, disseminated via twitter and charitable partners, aimed at previous, present and potential living donors (including public). 240 responses were received from all types of donors, with all ages represented, covering a good geographical spread. Limitations included a relatively small sample size, and under representation from BAME people, men, and people who have yet to refer/early contemplators. There was a smaller survey performed by GOLD in May 2020 which suggested more fear and anxiety about LDKT in Black people.
- COVID Response:
  - Recognised seriousness of the pandemic;
  - perception of general personal vulnerability due to COVID evenly distributed;
  - concerns about additional recipient risk was the greatest influence to donate or not;
  - keen to see programmes re-start;
  - high level of confidence in clinical teams and in the NHS;
  - testing (donors, recipients and staff) and PPE critical.
  - a willingness to undertake remote/virtual assessments where appropriate, move to another centre for surgery, be looked after by another clinical team if necessary.
- Next steps:
  - Continue to support all transplant centres to restart and expand LDKT;
  - Restore confidence in LDKT – public and patient engagement;
  - Review feasibility of October UKLKSS run;
  - Resume UK LKD Network activities – local/regional/UK-wide;
  - Complete 2019/20 LTI projects;
  - Resume UKLKSS development initiatives;
  - Progress business plan for living donation digital transformation;
  - Embed learning from LDKT 2020 into future strategy.

There is an information/resources page available on the ODT website at the following location: https://www.odt.nhs.uk/covid-19-advice-for-clinicians/

Questions:

Q1: K Modi: In relation to the law change since 20th May re. deemed consent in England, from next month when the specialist nurses have completed their training

To be ratified

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on this, deemed consent can have a negative impact on living donation. A consistent approach is required amongst clinicians, balancing the risks.
L Burnapp: There are already collaborations amongst transplant centres around the country. As we are currently coming out of a time of crisis experiences from this can be used to encourage people to realise that it is safe to move donors and patients around to different centres. Whilst the need to move things forward is recognised, different parts of the country are hit worse than others, and it is unknown where the virus will next hit. Ultimately, the aspiration to reduce variation needs to be addressed, but people also need to be supported as best as possible to ensure equity of access for transplantation.
R Ravanan: Some detailed research was carried out approximately 6 or 7 years ago showing variation but this is not associated with individual clinicians making more, or less risky decisions. R Ravanan will direct K Modi to some literature of work done in the UK around access to kidney transplants. **R Ravanan**

Q2: F Loud: What are the considerations immediately around the living paired scheme going forward in October?
L Burnapp: The whole intention of the restoration plan is to assess the feasibility of the matching run. Decisions will be made over the next few weeks as to whether it will go ahead (depends on the plans and proportion of transplants which can proceed). Need to address outstanding patients and those who need managing now. It is difficult to assess currently, but within the first 2 weeks of August colleagues, NHSBT and patients will be informed of what is going to happen.

6 Kidney Care UK – Patient survey: F Loud

F Loud reported on this survey which explores the impact of COVID-19 on people living with kidney disease. It was carried out online via social media from 7th to 15th May. The overall findings were: significant disruption to patient care, mental health issues, confusion around shielding advice, questions about what happens/what to do re. co-isolation with family members and for those going to work as well. The patients do really appreciate the care from the NHS given during this pandemic; this document is more about discovery and learning, and in the case of a second wave it is hoped to help improve some of the services in light of the findings.

- Methodology: 1211 responses. Majority of respondents were female (63%), lived in England (85%), and White British (94%).
- Key findings:
  - Disruption to care, surgery/appointments cancelled, feeling that check-ups could not be attended, felt unwell/anxious due to delayed/cancelled treatment, difficult to get advice about health worries/not knowing who to talk to.
  - Mental health: more than 4 in 10 patients felt they were affected or seriously affected in relation to isolation (shielding since March). People wanted mental and emotional support but had not received that and still have questions re. what happens next.
  - Worries around some people co-isolating (70%), and others in the same household still needing to go to work.
  - Some patients did not realise they had to shield: good communication needed as the Government advice was variable (and conflicting), not helping mental health. 13% of people in this survey were told not to shield and should have been.
  - Patients not knowing if they were eligible to get Government support, and how to get essential supplies such as food, and medications.

Another survey is being conducted in Wales at the moment, and Kidney Care UK plan to repeat this survey in a couple of month's time to learn about what is happening. This survey will be included as part of the minutes.

Not Signed

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Q1: K Modi: An analysis of around 450 calls to the NKF helpline during May and June mostly highlighted the following three concerns: shielding, mental and physical help; practical issues around going for a walk after isolating for a few months; parents of children who are kidney patients returning to school in September – what protection these vulnerable children should have.
R Ravanan: The British Association for Paediatric Nephrology (BAPN) have been working with clinicians and NHSBT, giving guidance. Children in general are less severely affected by COVID-19. No one aged less than 18 years post kidney transplant has passed away with COVID-19. BAPN are trying to build that into the guidance around mental health of the child as well, addressing the consequence of missing out on school, etc.

F Loud reported that as a charity, Kidney Care UK have heard that some people are not going to pause shielding because they are too nervous to go out, and that it is important to be aware of the long term impact of this. Secondly, re. vulnerable younger people, there is huge concern amongst those going back to work. There is a level of risk, and it is about trying to balance that risk out if a patient is on dialysis or has had a transplant. Some kidney patients face the huge decision re. whether they actually return to work or not (if they cannot work from home). It was noted that there is a lot of conflicting advice available through a variety of sources, and a lack of information, so it is important that patients are sign-posted to reliable websites.

7 Kidney Offering Scheme 6-month review: M Robb

Main points comparing the 2006 scheme with the new scheme:

- Key objectives of a new scheme:
  - Unify DBD and DCD offering, with all DBD and DCD kidneys allocated through the scheme;
  - More effective longevity matching between donor and recipient;
  - Better tailored HLA matching by age;
  - Geographical equity of access;
  - Waiting time from earliest of start of dialysis or activation on the list;
  - Age should be a continuous factor;
  - Avoid prolonged waiting times that are predictable using matchability.
- All deceased donor kidneys are allocated through the scheme: Tier A patients prioritised by matchability score and waiting time from dialysis; Tier B patients prioritised by point score.
- Data: activity: consistent trends comparing to the previous scheme (up to 10th March 2020).
- Transplant activity by region: higher proportion of kidneys going to the rest of the UK: there has been a high number of transplants going to tier A; also DCDs are going through the national offering scheme rather than retained locally. Although some kidneys are travelling further, more are now allocated to those difficult to match patients.
- Matchability and sensitisation: more transplants are going to difficult to match patients, including those who are more highly sensitised, female patients, those who are from a BAME background, and those with blood group B (normally these patients would wait a number of years for a transplant) – a sizable increase.
- An increase in transplants for those difficult to match patients.
- Some centres have a significant increase in activity under the new scheme. A lot more patients have had priority under the new scheme.
- Higher proportion of transplants going to the BAME groups: 33% under the previous scheme; 39% under the new scheme. Higher proportion of patients with blood group A transplanted.
- Not a large change in waiting time. Age: increase in older patients receiving a transplant – these patients have previously been difficult to match. Typically kidneys also coming from older donors. There has been a decrease in paediatric

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patients receiving a transplant, but this has been anticipated in the first 6 months (in the previous scheme there were a lot of difficult to match patients).
- In the first 3 months of the scheme, we anticipated no paediatric offers, but should resume usual levels at 9 to 12 months.
- Survival outcomes (the numbers are not risk adjusted yet): No evidence of difference in outcomes in graft survival or patient survival (3 months post-transplant survival).

Summary:
- Designed to improve equity of access to a national resource; more effective 'longevity' matching between the donor and recipient; avoid long waiting times that are predictable.
- Scheme went live on 11th September 2019.
- Highly sensitised, difficult to match, and BAME patients have improved access to transplant.
- Overall, the scheme has met expectations in the first few months.

To confirm, the one-year analysis will account for factors outside of the offering scheme during the COVID-19 period.

8 What would the Kidney Patient Support Group like the Kidney Advisory Group to do?

Views were invited from everyone on this call; a summary of the points are as follows:
- Using Microsoft Teams has worked well. It is always nicer to meet face to face and be able to network (a lot of people are missing the interaction in this current climate). It is also easier (logistically) for more people to be able to join a virtual meeting (difficult for those shielding, and time saving for some people to travel), and is more economical/kinder to the environment. Maybe these meetings going forward could alternate between face to face and virtual. Overwhelming majority for a hybrid option going forward. This depends what the venue situation will be at the end of this year or in 2021 and will be explored to try to make this work for as many people as possible.
- Consider more northern venue options to reduce travel time for those who live in the far north.
- Great to be able to share presentations on the screen.
- Agenda was informative and helpful, and possibly worked through more efficiently in a virtual meeting (for eg. due to limited interaction). Excellent information.
- The National Kidney Federation are keen to help with anything they can as an organisation.
- Would be very helpful to invite someone from the Renal Association/Renal Registry going forward. It was not known if the UK RR was currently hosting joint meetings with patient groups. R Ravanan and R Steenkamp will liaise with NHSBT colleagues and the President of the Renal Association in relation to preparing a joint presentation for this meeting going forward. **R Ravanan / R Steenkamp**
- Question: How will services be reconfigured in the context of COVID-19, taking into account there may be another spike? The KAG and clinical leadership team within NHSBT have had regular meetings in supporting centres to come back online, planning for the possibility of a second surge, and looking at how to decrease the impact on transplantation if this does happen. In terms of service reconfiguration: patients may be able to move between centres and this is being viewed as being more acceptable – people are feeling confident for that to happen which will help.the NHS when it is essentially trying to work towards stability.
- Good to see the number of transplants increasing again, a relief to patients.

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- Thanks to the NHS staff in terms of what they have gone through, unbelievable.
- Really valuable meeting, and it would be of benefit for patient organisations to be able to engage more with NHSBT during the year going forward to gain patient feedback.
- L Burnapp reported that a reflections document is being drafted within the wider clinical team at NHSBT which examines how some things can be done differently given a second wave. There has been a section produced around the patient voice, how we liaise within a crisis, and before and after a crisis. This section aims to formalise the approach; different patient groups (for different organs) will be asked their views to check we are on the right track with issues and guidelines.
- If patient groups need anything further from these meetings going forward, please contact R Ravanan and D Marshall.

9 Any Other Business

R Ravanan concluded the meeting with a sincere expression of thanks: despite all of the significant troubles, anxiety, concerns about health, having to completely navigate a new NHS system - the comments received have given us the energy to continue to do what we love doing, we are humbled, thank you very much. In terms of ODT: the promise is to be more prepared for second surge and aim to avoid disruption as much as possible. There is lots to be learnt, and quickly; the goal for the next 6 months or so is to share learning through this forum. Please stay in touch and contact us with any queries. Thank you all.

Date of next meeting

TBC

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