NHS BLOOD AND TRANSPLANT
ORGAN DONATION & TRANSPLANTATION DIRECTORATE

MINUTES OF THE TWENTY FIRST MEETING OF THE KIDNEY PATIENT GROUP HELD ON WEDNESDAY 21st JULY 2021 VIA MICROSOFT TEAMS

PRESENT:

Rommel Ravanan	Chair of NHSBT Kidney Advisory Group – **Co-Chair**
David Marshall	**Co-Chair –** Kidney Patient Group
Lisa Burnapp	Clinical Lead Living Donation, NHSBT
Andrea Brown	National Kidney Federation
Rebecca Curtis	Statistics & Clinical Research, NHSBT
Brett Dowds	Kidney Wales
Tess Harris	Polycystic Disease Charity
Fiona Loud	Kidney Care UK
Kirit Modi	National Kidney Federation (left at 12:00)
Tracey Murray	Kidney Research UK
Andy Henwood	British Renal Society, Kidney Patient Involvement Network (KPIN)
Matthew Robb	Statistics & Clinical Research, NHSBT
Jan Shorrock	Give a Kidney (left at 12:30)
Retha Steenkamp	Head of Operations, UK Renal Registry

In Attendance:

Sam Tomkings	Clinical & Support Services, OTDT (NHSBT)
Claire Williment	To present item 4

Apologies:
Chris Callaghan, National Lead for Organ Utilisation (Abdominal)
John Forsythe, Medical Director, OTDT (NHSBT)
Julia Mackisack, Lay Member
Aamer Safdar, Lay Member
Robert Wiggins, Give a Kidney Charity

1 Welcome and Introduction **ACTION**

Members of the meeting were welcomed and were thanked for joining. It was announced that this meeting was being recorded for the purpose of the minutes only.

2 Approval of minutes from previous meeting – KPG(M)(20)1 and Action Points KPG(AP)(21)1

The previous minutes were agreed as a true and correct record and the action points with a verbal report are listed below.

AP4: Development of a BAME strategy on organ transplantation: post 2020:
R Ravanan and K Modi discussed what research has been done in the UK and information on that has been shared. This will be discussed further as the strategy develops.

AP5: Collaborative working on the National UK Kidney Sharing Scheme:
L Burnapp reported that due to the practical challenges for patients travelling between countries, the fixed term working group continues to work with the Netherlands which ran into some significant Governance issues from the Dutch side in terms of the information they could share with the UK and are still navigating that. This work will continue to progress throughout the year.

3 Medical Director's Report **ACTION**

R Ravanan presented the Medical Director's report on behalf of J Forsythe who sent his apologies due to an urgent matter which arose this morning.

The NHSBT strategy which many people on this call have been actively involved in writing was approved by the DHSE earlier in the year. There were plans for more formal publicity of the strategy but for various reasons did not get as high-profile visibility that was hoped for. The final version of the document is available on the NHSBT website.

The key points from the document are that for the first time NHSBT's strategy programme straddles both organ donation and transplantation. The document balances evolution of best practice and revolution, mainly technology aided to enable some of the key visions of the strategy. The two big drivers are the Opt-out legislation and lessons learned from the pandemic. One of the key pillars is that people from all backgrounds have timely access to organs and working with the Government and the providers to ensure we have a sustainable service. Plus, a lot of focus on recipient outcomes and research and innovation to help the programme and the service lead into the following decades.

Kidney transplantation has been around 80% of a normal year's activity with deceased donor transplant activity being in a slightly better position than living kidney donor activity due to loss of access to theatres, surgeons etc. There are concerns about the current COVID surge as transplant patients tend to have poorer outcomes than non-transplant patients, however transplant patients were prioritised for vaccination early on. Around 83% of transplant patients have had both vaccination doses however, it was acknowledged that some regions have reported less penetration mainly in the capital and there was some variation based on ethnicity.

Questions:
What are going to be the measurable outcomes over the next 5 years and how will that be funded and how will the implementation be planned? C Williment advised that there is work underway within NHSBT to identify what goes first particularly in the financial situation we are finding ourselves in and prioritisation in terms of co-dependencies which is being thought through. A new programme has been set up in NHBST looking at organ utilisation from deceased donors to increase organ donation. Some of the actions from that are up and running such as, established clinical leads in utilisation to identify what the barriers are for organ donation and what can be done to increase accepting organs. Another aspect of the organ utilisation programme (OUG) is looking at establishment for assessment and recovery (ARC) centres and taking more marginal organs and placing them on machines in those centres. The OUG will look at how we can improve imaging and data sharing.

L Burnapp added that a lot of discussion had taken place in the strategy development group about what outcomes we would like to see and although this is not in the document, internally, those measures that were discussed in the strategy group and the things that are important to patients are still in our thoughts, particularly around the diversity metrics, donation, transplantations etc.
L Burnapp assured those discussions are taking place internally.

4 **Organ Utilisation Group (OUG)** **ACTION**

C Williment gave a presentation on the OUG which was established to facilitate transplantation.

To access the presentation, please click here

C Williment would be grateful if people could get in touch and provide views and thoughts with where improvements can be made.

Questions
What is the drumbeat and pace of the meetings and how the decisions will be communicated back out? The OUG will meet every 6 weeks and are still in the process of establishing that for the stakeholder forum. If there are requests for someone to attend and present more information about this to let C Williment know.

C Williment requested colleagues look out for emails and the online request for evidence and stakeholder workshops and C Williment will let colleagues know when the website is up and running.

5 **Activity Update**
M Robb presented an update on kidney activity & 2019 Kidney offering scheme and an update on COVID vaccination in transplant patients.

To access the presentation, please click here

Paediatric update
The number of paediatric patients on dialysis has grown quickly over the last 15 months which is mainly a problem in England and some centres were under immense pressure as their dialysis population has grown by 50%.

A task and finish group has been set up by KAG and a series of recommendations were put forward which are currently with NHS England to work out how they will support the paediatric community.

Questions
What efforts are being made to encourage the unvaccinated to get their vaccines? R Ravanan added that the early look at the data shows that the two doses protect you from dying from COVID compared to not having the vaccine and have sign posted areas where there has been less vaccine penetration to help those centres target patients to try to get the vaccines done. More time is required to look at what the effects from the vaccine are and how much additional protection would transplant, or kidney patients require in terms of shielding. NHSBT are working with NSHE&I colleagues to see if there are any additional measures that could work for this patient population. The BTS and NHSBT sent out a joint communication and are aligned with their FAQ for clinicians and patients and as soon as new information is available, it is updated in the FAQ. L Burnapp requested help from colleagues on this call to encourage patient groups to get both vaccine doses. L Burnapp welcomed thoughts from the groups on the FAQs.

R Ravanan asked members of the call what some of the top concerns raised by the patient groups are.

T Harris highlighted that most people are discussing antibody testing. R Ravanan stated that the official NHSE&I guidance is to not do antibody testing because the test on its own is most likely unhelpful and clinically, that is the same conclusion that NHSBT has come to. Laboratory work suggests that transplant patients have lower

antibodies than non-transplant patients which is a cause for concern, but it is not known what that means biologically. The national guidance has already mandated that for immunosuppressed patients, a booster dose of the vaccine will be offered from w/c 6th September. **ACTION**

F Loud added that patients are buying the antibody tests and are taking false assurance from that or unnecessary panicking from what they are seeing. Patients feel that very little is in their control at the moment and the antibody tests are one of the things available. L Burnapp asked what we could do collectively. F Loud suggested that we must be strong on the message that if you have both vaccines you are better protected, and it may be time to consider something like infographics about the vaccine data which could be added as a separate link or an information session or webinar. M Robb advised the big piece of work is looking at the robust analysis of the outcomes following vaccination and presenting that information in a way that is useful for patients.

6 Living Donor Kidney Transplant update

L Burnapp presented an update on Living Donor Kidney Transplant to the group.

To access the presentation, please click here

L Burnapp thanked colleagues who have contributed to forming the strategic direction for the next 10 years and to all the work colleagues have done in the past 10 years.

L Burnapp requested that if colleagues feel there is something which should be done and included to let her know.

Something recently discussed is more awareness around the kidney sharing scheme and the impact for children, because around 10% of children have received a transplant through the sharing scheme. Even though a donor may be considered unsuitable in terms of age or HLA match but may not think to discuss whether they could go into the sharing scheme and get a younger donor which could be a real opportunity.

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

K Modi stated that 80% activity on organ transplantation is remarkable, however if you look at the broader picture, we know that for a variety of reasons, including fewer transplants taking place both donation after death and living donation, that kidney patients have suffered greatly over the pandemic. There have been large numbers of patients who dialyse in a hospital and have been affected by COVID and a large number have died because of that. K Modi asked what advice and support we can give to local referral and transplant centres to provide better and fairer services for recipients. K Modi felt the key issues are the unexplained variation in provision across the country and the other is the inequality issue particularly in this context and access to waiting list for people from the BAME background.

R Ravanan acknowledged that the history of the Kidney Patient Group Meetings was for NHSBT to interact with patient stakeholders which is very much transplant focused, however, following a request at the last meeting for joint working between the NHSBT Kidney Patient Group and UKKA and involving a member of the Renal Association to partner with the UKKA and do a joint presentation at these meetings. This work is in progress.

Detailed research work goes to show that most variation can be explained and identified that some element of it is centre variation but a lot of it can be explained on a case mix i.e., some units care for higher proportion of patients with more comorbidity burden.	**ACTION**
R Ravanan reiterated that kidney transplant waiting lists have nearly fully recovered to where it was before the pandemic started and the breakdown of the active list by ethnicity is pretty much back to how it was in February 2020. A change was seen at the first few months of the pandemic but that was linked to different areas of the country which were more or less affected by the pandemic, for example, a lot of the London centres closed, and Birmingham closed who have a higher percentage of BAME population. R Ravanan asked if there is any specific data that the NKF would like to see, this can be provided.	
K Modi felt there are underlying issues which shows if you are from a BAME background that your chances of getting on the waiting list are lower and if you are from a certain BAME background, your chances of getting a pre emptive transplant are lower. The thrust of the GIRFT report published by NHS England is about addressing unexplained variation within the kidney services. K Modi would like these topics included on the next agenda of this group.	**R Ravanan**
F Loud raised the mental health factor of this as people will not recover from this for a long time and whether there is anything this group could do to help. F Loud pointed out that the RSTP have established a number of cross cutting areas that each of the work groups have established that psychosocial health support is a cross cutting theme of those groups and there will be a duty for all of those groups to report back and it may be that Nick Torpey could do this and to link in with this group. L Burnapp added that one of the ambitions in the strategy is to collect self-reported data which should be able to pick up those mental health and quality of life aspects. L Burnapp advised this is something that is being done in living donation but currently, as a paper form.	
F Loud felt the number of patients who are suspended is worth looking at as the numbers are quite high. R Ravanan confirmed the outcome of patients who are suspended are regularly looked at as part of every advisory group and will look at a way of bringing that to this group.	**R Ravanan / M Robb**
F Loud suggested discussing next time what has been learnt about the variations and what can we do as we found there were some things that could be done very quickly to address that, such as, the London collaborative for example and the innovation that came in place and those that will stay because they were good ideas which helped address some of the capacity issues. R Ravanan advised that the Clinical Team Meetings are looking at what has worked well and to ensure those innovations are sustainable. Work is ongoing for that and will look at how this can be fed back into this group.	**R Ravanan**
R Ravanan proposed that any further suggestions on how a combined transplant and registry/UKKA group meeting could work to email R Ravanan and S Tomkings.	

8 Any Other Business

J Shorrock thanked the group via email for reporting and all their work.

NHSBT now have a new patient-information website https://www.nhsbt.nhs.uk/organ-transplantation/ and R Ravanan requested colleagues on this call take a look at this and give feedback on whether it was helpful and as a patient, would it help make decisions.

ACTION

Feedback can be sent to S Tomkings. **All Members**

A Henwood is keen to find out how the KPIN can help. R Ravanan requested if there is anyway that we can get a message to the patients to identify reasons for not taking up the vaccine offer and/ or encouraging the unvaccinated to get both doses at the earliest opportunity.

A Brown from the NKF suggested putting an article in kidney life about living donation and the sharing scheme. L Burnapp agreed and suggested that it would be helpful to include the child focus side of things and to include a case study perhaps in the next newsletter later in the year.

A Brown advised that the UKKA president is writing a letter to the JCVI about the third dose of the vaccine and are meeting tomorrow to hopefully prioritise kidney patients. A Brown suggested that patient messaging needs to be very clear and highlighted that NKF, Kidney Care, PKD, UK Kidney Association and Kidney Wales are working together as a kidney charity together comms team which A Brown suggested would be useful for someone from NHSBT to join up with that and think of some joint messages which can be put out there. R Ravanan agreed the joint comms team is a good idea for NHSBT to link up with and requested that the meeting facilitator could contact both him and L Burnapp who will arrange for someone from NHSBT to join this. **A Brown**

T Harris would like to ensure that PKD are included in all correspondence and thanked R Ravanan for the paediatric update.

Members of the group thanked NHSBT for the information which has been and continues to be provided.

R Ravanan and D Marshall thanked all for joining today's meeting.

Date of next meeting
TBC