Briefing paper for the APPKG Summit on Living Kidney Donation

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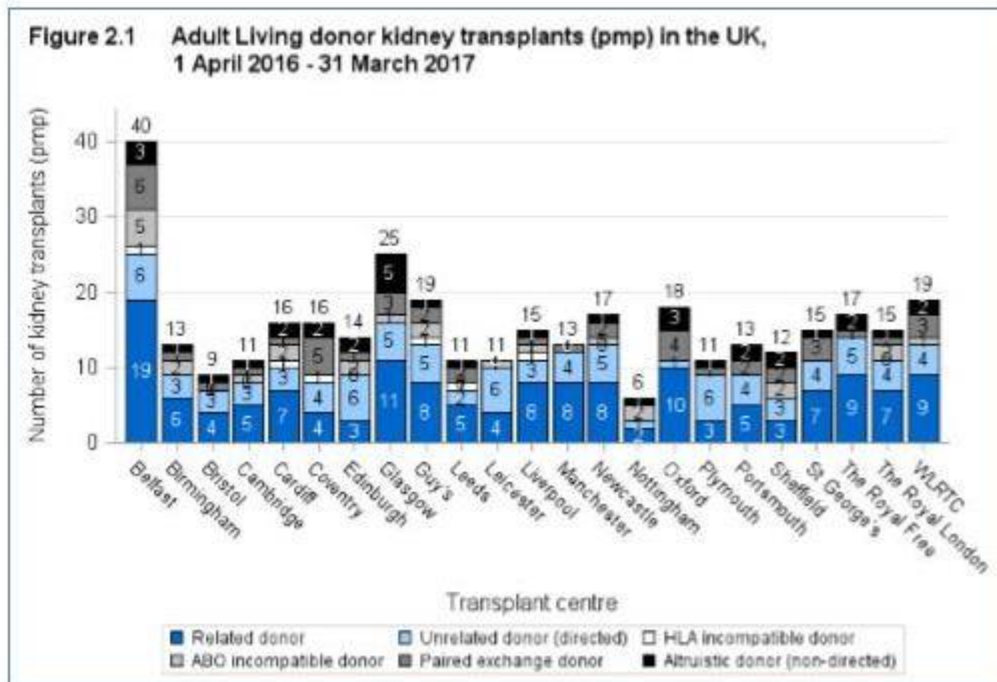
1. Introduction

This briefing paper is published to facilitate an informed discussion on living kidney donation in the UK at the Summit. The NKF published a Discussion Paper on Challenges facing living kidney donation in the UK in June 2017 (https://www.kidney.org.uk/assets/Uploads/Discussion-Paper-final-NKF.pdf) and invited responses to it. A summary of the twenty responses received is set our below, Appendix 1. Overall, the quality of the responses received was very high and it is a pleasure to incorporate the main issues raised in this briefing paper.

2. The number of living donors in the UK has decreased since 2013/14. In 2016/17 there were 1043 living donors compared to 1148 in 2013/14; which is a decrease of 9%. The target set in the Living Donor Kidney Transplantation 2020 Strategy (LDKT 2020) is 1728. This means that we need an increase of 685 living donors (nearly 65%) on the 2016/17 figure to meet the 2020 target. The latest data from the first six months of the 2017/18 financial year indicates that the number of living kidney transplants has gone down (490 compared to 496 during the same period in the previous year) and that the number of live kidney donors per million of population (pmp) for the UK has also gone down (7.50 pmp compared to 7.65 during the same period in the previous year). NHSBT published 2016/17 living donation data, pmp by transplant centres in November 2017, for the first time. This shows the wide range between 40 pmp at Belfast and 6 pmp at Nottingham.



3. The Discussion Paper suggested four possible reasons for the drop in numbers.

- **R1:** Unexplained variation in the number of living donor transplants undertaken by transplant centres.
- **R2:** Some hospitals do not employ sufficient Living Donor Co-ordinators (LDCs).
- **R3:** The support provided by LDCs in encouraging potential living donors may need to be reviewed.
- **R4:** Some kidney patients may prefer to receive a kidney donated after death rather than one from a living donor.

The responses to the Discussion Paper indicate that, while all four reasons are probably valid, there may also be other reasons for the drop in numbers, which are set out below.

4. Other possible reasons

R5: Clarification of roles and responsibilities for implementing the LDKT 2020 Strategy in England.

The arrangements for implementing the LDKT 2020 in England at a strategic level are complex.

The Secretary of State makes arrangements for facilitating organ transplantation and the Department of Health takes an overarching view on all forms of donation and transplantation. The Secretary of State has delegated this function to NHS Blood and Transplant (NHSBT) in the main but, of more

relevance to living donation, has given commissioning responsibility to NHS England (NHSE) for everything to do with renal transplants.
NHSE commissions:

- All transplant related care provided by adult specialist renal and transplant centres; including work up of potential living donors
- All transplantation activity provided by adult renal transplant centres; including living donor nephrectomy.

Commissioned providers must demonstrate compliance with the specialist services service specification.
NHSE also fund living donor co-ordinator posts.

NHSBT have the responsibility for monitoring donor and recipient outcomes, providing relevant statistics, developing and administering the UK Living Kidney Sharing Scheme, engaging with professionals, patients and the public to raise the profile of LDKT and fostering innovation to support increases in activity and providing professional leadership for LDCs.

The 2020 Oversight Group is responsible for holding to account all partners for their role in delivering the strategy. It is not clear to whom the 2020 Oversight Group is accountable.

Finally, the 2020 Strategy Implementation Group (SIG) is responsible for developing the plan for action and delivering it.
A clearer outline of roles and responsibility would be helpful in ensuring that each body effectively delivers on its responsibility. The SIG reports to the 2020 Oversight Group and the Senior Management Team of NHSBT.
The arrangements in the Scotland, Wales and Northern Ireland are more straightforward. For example, in Scotland, transplantation is commissioned by the National Services Division. In Northern Ireland, the Department of Health is responsible for all renal replacement therapy across the five Trusts.

R6: Establishment of better structures in hospitals for living donation.
The recent request from NHSBT to hospitals to appoint a lead nephrologist for living donation is most welcome and has received a positive response. However, no time is allocated to this person to undertake this new role. It is important that NHSE and the commissioners in Scotland, Wales and Northern Ireland, provide funding (say for half a day a week) to hospitals for this work to be undertaken well throughout the country. Secondly, for donation after death, there are local Organ Donation Committees (ODCs) in hospitals. It would be helpful to consider establishing a similar local group with

responsibility for living donation. One way would be to extend the role of the ODCs to include living donation as well, and invite the lead nephrologist for living donation and the lead LDC to join this group. This could also help increase collaboration between both types of donation in hospitals.

R7: Consider developing an outreach programme to encourage more living donors.

NHSBT's survey in January 2017 showed that fewer than 48% of the participants knew that it was possible to donate a kidney as a living person. It is very difficult for a patient waiting for a kidney transplant to raise this matter with close family members and friends without support. We currently do not have any proper arrangements for doing so. We know from the outcome of the ATTOM study mentioned in the NKF's Discussion Paper, that the likelihood of LDKT compared to Deceased Donor Kidney transplantation (DDKT) is significantly reduced if the recipient is older, from Black and Minority Ethnic (BAME) background, is divorced, separated or widowed, has lower educational attainment and experiences socio-economic deprivation. The work through National (Black and Ethnic Minority) Transplant Alliance (NBTA) and Kidney research UK (KRUK) among BAME communities also mentioned in the Discussion Paper is most relevant and, once evaluated, can be used to develop a national outreach programme to offer practical support to those waiting for a kidney transplant in finding a potential live donor. This may involve support provided at home or within the community. It can be offered by trained living donors, recipients and LDCs. The effective development of this service will need commissioning by NHSE and others, as well as funding to embed this service throughout the country. We know that significant level of savings to the NHS would be made by increasing kidney transplants and reducing the number of patients on dialysis.

R8: More consistent assessment of the risk for potential living donors.

It is very important that the risk to a potential living donor is assessed by clinicians carefully, taking account of the latest research, and that the potential donor is able to make an informed decision on whether to go ahead or not. It is not apparent if the current guidelines to clinicians are sufficiently clear and there is some evidence that there is inconsistent practice among transplant centres. For example, the criterion for Body Mass Index (BMI) acceptable for a potential donor seems to vary between 30 and 35. The British Transplantation Society (BTS) is currently developing revised guidance and this is most welcome. Once finalised, it is important that all hospitals follow these to enable a more consistent risk of assessment is established in the UK.

R9: Make the assessment process for potential donors quicker and easier.
The excellent examples from Belfast and Teesside included in the Discussion Paper highlight the importance of making the assessment process quicker and easier for potential donors. The potential donor should be treated as a Very Important Patient (VIP) by hospitals. Lead nephrologists for living donation in hospitals, LDCs and surgeons should champion their care within hospitals. NHSE and other commissioners can help by providing financial incentives to hospitals if they complete the assessment process in good time.

R10: Need for urgency.
The downward trend in the number of living donors in the UK seems to be continuing, despite considerable efforts to improve the situation and some excellent practice. A sense of urgency is now needed to reverse the trend. For example, NHSE oversaw a peer review of all transplant centres. This has been generally received well and interim findings were shared at a national conference. However, the final report on the findings from this work has not been published; nearly a year after the review. It is clear that effective joint working by everyone involved in living donation, together with a need for urgency, is essential for us to improve.

5. Conclusion

We know that there are many reasons for the drop in the number of living donors and that these are complex. The eight reasons identified above provide a starting point for further discussion at the Summit on 22 November 2017. We expect that these discussions will lead to a set of recommendations which the APPKG will publish following the Summit. It is important that we reverse the current downward trend. The NKF will, of course, continue to work with others in increasing living kidney donations in the UK.

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Appendix 1

Summary of the responses to the NKF Discussion Paper on Living Donation

The NKF was very pleased to receive a very good response to the Paper. Twenty responses, from a wide range of groups and individuals were received. Responses were received from all NHS linked organisations responsible for living donations, kidney charities, Kidney Patients Associations, professional associations, hospitals and individuals. Overall, the quality of the responses was very high; respondents had carefully considered the issues and spent considerable amount of time in formulating their responses. The NKF is most grateful to everyone for their responses. A summary of the responses is set out below. We have not named the respondents because it would not be appropriate to do so without having the permission of the respondents. Respondents may publicise their responses separately.

1. Response 1

More needs to be done to educate patients and relatives on the benefits of transplantation; perhaps by LDCs going out to meet the relatives of patients to explain how they may be able to help by donating a live kidney to a close relative.

2. Response 2

We need a radical approach going forward. The excellent work in Northern Ireland and Middlesbrough should be used to encourage less performing areas to improve. All potential living donors must be treated as “best customers”, and the path to donation should be as smooth as possible. It is essential that every area has sufficient LDCs.

3. Response 3

Socio–economic deprivation will have a severe impact on the ability of a patient to maintain a healthy lifestyle and make the necessary journey.

4. Response 4

The reports from the two high performing regions (Northern Ireland and Teesside), provide valuable evidence of the results that may be obtained, from which lessons can be learnt. These initiatives have shown a proven increase in live donor transplants and should be recommended for use elsewhere in the UK.

5. Response 5

More emphasise should be placed on all nephrologists to approach living donation with their patients and not just have a lead nephrologist at each centre.

6. Response 6

Simplify the paper into plain English and a shorter format. Make the public aware of the ease of being a live donor. Demonstrate the positive outcomes of a living donor can bring. Take a serious look at national TV promotion. The kidney community should shout about these issues, not in hushed tones in hospital corridors, wards or board rooms.

7. Response 7

A formal trial aimed at supporting people with kidney disease to find a living kidney donor, particularly aimed at supporting people from socio-economically disadvantaged groups is taking place in the UK.
Research into why people who are socio-economically disadvantaged are less likely to get a living donor transplant has suggested that:

- They face difficulties early on in the process.
- They are less involved and less confident at having discussions about their treatment.
- Some doctors were less good at engaging them in these important discussions.

8. Response 8

The paper is a helpful analysis of the current situation regarding living donation and will inform debate on how optimum levels of living donors can be achieved.
The target for LDKT for 2020 was ambitious. The targets for both living and deceased transplantation have to be seen together; the right balance will achieve better outcomes for patients.
The work being done by NBTA and KRUK mentioned in the paper, once evaluated, may need to be followed up by larger follow on studies.

9. Response 9

Since 60% of patients who need a kidney never ask anyone to be a living donor, a programme to support these patients should be considered. Examples of such work include the Living Donor Advocacy scheme at the Royal Free Hospital and the work mentioned in the Paper by NBTA and KRUK. Kidney Charities would be willing to support the development of this approach. The

significant financial benefits for the NHS of a kidney transplant for a patient on dialysis should be highlighted and further resources be allocated to ensure hospitals have sufficient living donor coordinators in post at all times. A commissioning model based on capital payment (i.e. tariff based on whole cohort or population) should be considered. This would free up sufficient resources across all providers of integrated services, including hospitals, renal centres and patient groups.

10. <u>Response 10</u>

The system supporting living donation in the UK has been created spontaneously and it is time to review the resources and capacity available. A complete national review of the present arrangements should be undertaken and a fully planned service with adequate resources to ensure that suitable living donors are accepted more quickly, no matter where they live. Long term outcomes for donors must be properly monitored and information for prospective live donors must be adequate in order to make fully informed decisions. Research shows that black or older kidney patients may receive fewer living donations because they may be less likely to approach potential donors. A combination of commissioning, quality improvement, targeted intervention backed by learning from research and outreach programmes should be used to formulate an improvement programme which addresses the barriers.

11. <u>Response 11</u>

We support the LDKT 2020 Strategic Plan and are committed to a collaborative approach needed to increase transplant activity along with others.

12. <u>Response 12</u>

We strongly support LDKT and recognise the contribution that it makes to overall transplant activity and quality. The LDKT 2020 Strategy sets out ambitious activity targets which may be challenging to achieve given the rise in deceased organ donation. The NKF Discussion Paper reflects the trends in donation and transplantation activity and identifies areas of improvement to increase LDKT. We endorse the strategy implementation group action to address the challenges, recognising that they are multi-factorial and complex. We believe that engagement across the wider transplant community –health departments, commissioners, professionals and donor and patient associations-is essential to maximise LDKT activity and ensure equity of access for all potential recipients. We are committed to playing an active role to underpin all aspects of transplantation across the UK. We are keen to work in partnership with the third sector to support this agenda.

13. Response 13, 14 and 15 (on behalf of three groups)

The aim of the LDKT 2020 Strategy is to match world class performance in LDKT. Regional variations in LDKT activity are well documented but there is limited evidence available to identify the underlying causes. Shared learning events arranged by the LDKT 2020 Strategy Implementation Group to explore these variations have taken place with a view to create local action plans. There are examples of excellent practice in LDKT throughout the UK but every region has scope to improve. This has resulted in a request to establish a lead nephrologist for living kidney donation in each referring unit and transplant centre. Work on improving data on living donor kidney transplantation rates (per million of population) by transplant centres has started and will be published soon. Also, arrangements for including non-directed altruistic donors in the UK Living Kidney Sharing Scheme from January 2018 are being made.
A summary of the roles of most of the bodies responsible for living donation in England are included in this response.
To support workforce planning, NHSBT has developed a tool that can be used by transplant centres and referring hospitals to calculate the number of LDCs they need. There is a commitment from NHSE to include this in the specification for LDKT.
Awareness about living donation is low but improving; fewer than 48% of participants in a survey conducted by NHSBT in January 2017 knew that it was possible to donate a kidney as a living person. A wide range of updated on-line resources are now available across the UK. Further work to provide bespoke information on specific topics of interest to different communities is in progress. The projects aimed at BAME communities led by NBTA and KRUK are ongoing and offer opportunities for inclusion in local plans across the country.
Feedback from clinical teams suggests that the success of strategies to increase deceased organ donation, with consequent reduction in waiting times and a consequent fall in the number of patients waiting for a transplant has impacted on the number of LDKT procedures. The small but real risk to the donor, combined with the perception of that risk by the potential recipient, may encourage patients to make decisions in favour of a deceased donor kidney transplant rather than LDKT.
Other implementation priorities include:

- Development of non-mandatory transplant tariff in England from April 2018 and mandatory tariff from April 2019.
- Continued engagement by all four departments of health to align activities and campaigns.
- Publishing LDKT pmp data for all UK transplant centres and referring units by 2018/19.

- Developing further donor and recipient resources to support decision making.
- Embed Donor Reported Outcome Measures in collection of follow-up information.
- Making it easy for people to donate by removing identified barriers to LDKT.

The LDKT 2020 Strategy sets out ambitious targets for success, which are dependent upon collective effort to deliver.

16. Response 16

The Discussion Paper is impressive but there is an omission related to the Transplant First project which is part of Kidney Quality Improvement Partnership (KQuIP). The aim of Transplant First is to address unwarranted variation in access to renal transplantation, focussing on pre-emptive wait listing and transplantation. An extensive suite of resources has been developed by West Midlands, and promoted nationally. Transplant First is being promoted through a series of regional events in 2017 and 2018. Each unit reviews its transplant activity, their pathway and leadership and develops a 3-year plan of improvement. Like the NKF, KQuIP are committed to ensure that transplantation remains at the forefront of everyone's mind.

17. Response 17

Currently, no financial incentive is allowed to a potential donor in the UK. This prohibition needs to be re-examined. We need to produce something new and inducements would fit the bill. To go on with altruism alone will not save these lives and suffering, we are failing these people for lack of courage.

18. Response 18

We recognise that for some donors the work up process can be quicker and more direct. We are currently in discussion with other departments in the hospital about access to investigations so that we can provide several on one day. This will improve the convenience for donors.
We are also expanding the number of transplant surgeons.

We now provide transplant education evenings three times a year with the transplant team travelling to the locality of the patients rather than coming to the main hospital.

19. Response 19

There is some anecdotal experience of BAME having living donors who live abroad and there are difficulties in getting visas to come to the UK. Also, some recent evidence that a higher proportion of potential living donors either drop out of the work up or complete the work up but do not progress to donation.

20. Response 20

The Netherlands have the best living donor rates in the world. It would be helpful to find out about their approach so that we can learn from it.
The commissioning process should include financial incentives for hospitals to increase assessments and live donation; this will help change attitudes in some hospitals.
The guidelines for assessing the risk for potential donors are “wishy-washy”. This results in different approaches to assessing risk within hospitals.