



## **Pre-Emptive Transplantation Defining the Future for Black People Living with Chronic Kidney Disease**

This proposal outlines a model of improvement by Gift of Living Donation (GOLD) to implement a change to the current renal pathway at Imperial College Healthcare NHS Trust, to ensure that black pre dialysis kidney patients have access to culturally tailored education, information, and support to increase their chances of receiving a pre-emptive living donor kidney transplant.

### **Background**

Living donor kidney transplantation offers people with end stage kidney disease the best opportunity for a successful transplant, with excellent donor, recipient, and transplant outcomes. It is the only option that offers the patient and their family a chance to plan transplantation and to avoid commencing dialysis, which has a significant impact on people's lives—especially Black and Asian people who spend longer on dialysis.

Research has identified that people from a Black, Asian, Mixed-Race, and Minority Ethnic (BAME) background in the UK have reduced access to living donor kidney transplantation and during the COVID-19 pandemic, this group was also identified as amongst the most disadvantaged, which has resulted in a 60% reduction in overall living donor transplants.

As renal teams move into the long-term work of reshaping and changing the way they work due to COVID 19, they will need to address the health inequalities highlighted during the pandemic, especially its impact on the number of black people on dialysis and the low number of black living donor transplants. Some questions may need to be asked, such as what improvement initiatives have been implemented to change the status quo? have they been successful? If not, why? How can we change the way we do things to promote health equity for black renal patients? GOLD believes the phone buddy scheme as a model of improvement could offer a long term and sustainable solution to increasing the number of black pre-emptive living donor transplants.

Based upon international and UK experience, evidence suggests that targeted interventions which adopt a clinician and community collaborative approach are likely to be the most successful in engaging, empowering, educating, and enabling patients in their decision-making and increasing the opportunities for suitable recipients and potential donors.

It is important that interventions are 'tailor made' to address the needs of different patients from a range of backgrounds—i.e., culturally competent, culturally sensitive, and delivered and implemented at a local or regional level.

As a stakeholder with NHSBT, GOLD has been involved in collaborative initiatives to improve access to living donor kidney transplantation for people from an African-Caribbean background in London and the Midlands. These initiatives although haven't directly resulted

into transplants for patients or formed evidence-based data, they have resulted in:

- Family and friends coming forward to be assessed for living donation
- Increased patient confidence and understanding of living donation
- Production of culturally relevant living kidney donation resources and tools
- Increased number of enquiries about living donation from family and friends

### **Organ Donation and Transplantation, Meeting the Need, NHSBT's Ten-Year Strategy for Organ Donation and Transplantation in the United Kingdom.**

As set out in NHS Blood and Transplant's 'Organ Donation and Transplantation 2030: Meeting the need' will only be a success if it supports and benefits everyone in need of a transplant." Whilst progress has been made, an unacceptably large number of people from an African-Caribbean background still spend far too long on the transplant waiting list because of a lack of suitable organs. The importance of a strategic approach to addressing issues related to the black community has been highlighted throughout NHSBT stakeholder events. This has been brought into sharper focus because of the disproportionate impact of COVID-19 amongst people from a BAME background and the greater awareness of systemic racism in society and efforts to address it through the Black Lives Matter movement.

#### **NHSBT Transplant Activity Report: 2014-2021 Table 1**

Number of living kidney donors in the UK, by ethnicity and financial year, 1 April 2014–31 March 2021

Ethnicity	2014/15	2015/16	2016/17	2017/18	2018/19	2019/2020	20/21
White	929	939	900	923	890	846	369
Asian	76	72	79	75	83	81	33
Black	38	29	18	17	25	26	8
Chinese	6	2	7	10	7	7	2
Other	35	35	36	35	27	21	10

The data in Table 1 shows there has not been a significant increase in the number of black living donors nationally over the past 6 years and the numbers remain very low compared to other ethnic groups. (Year 7 COVID 19) There is an urgent need for us to intervene to address this disparity, reduce the burden of dialysis on black patients and improve their quality of life. The data identifies an opportunity for a model of improvement to be implemented to ensure black patients have the best possible healthcare outcomes.

#### **Why a model of improvement targeting black kidney patients is urgently needed now.**

If nothing is done to change the outcomes by the twin evils of inequality and racism

- Black patients will continue to face health inequalities in kidney care
- We will see an increase in the number of black people needing dialysis
- Black patients will continue to have unsatisfactory health outcomes
- Black people will continue to mistrust healthcare providers and professionals
- It will confirm the lack of compassion, care and empathy black patients already feel

However, if we implement a model of improvement for black kidney patients, it will:

- Offer patient-centred kidney care
- Help to regain trust and build better relationships
- Promote health equity
- Improve the human cost of CKD
- Improve health outcomes
- Improve living donation data, research, and shape future strategies
- Potentially increase the number of pre-emptive transplants

As an organisation, our vision is to see sustainable and long-term improvements in the health and wellbeing outcomes for black people effected by chronic kidney disease. We are committed to working in collaboration with healthcare professionals and key stakeholders to deliver practical and realistic improvement solutions in order that every black person in need of a kidney transplant stands a better chance of having one.

### **Applying Quality Improvement Methodology:**

#### **Our Aim Statement: what are we trying to accomplish?**

- Improve pre-emptive transplants rates for black patients within 12 months.
- Work towards an early approach from clinicians and nurses with black patients within 1 month of their 1<sup>st</sup> appointment, allowing for timely engagement between suitable patients and peer buddies.
- Improve patient access to culturally relevant information, education, and supportive care.
- Reduce the number of black people needing dialysis.
- Living donation becomes a normal choice for black people.
- Improve willingness of family and friends to consider living donation.

#### **How will we know that a change is an improvement?**

Need to add baseline data from the Trust here as a starting point.

#### **What change can we make that will result in an improvement?**

Introduce a culturally tailored community intervention in the renal pathway for black patients.

#### **The Peer Phone Buddy Scheme**

The peer phone buddy scheme is a community initiative which was set up by GOLD during the pandemic to provide support to black kidney patients. It is run by a team of trained, black living donors and donor recipients who are knowledgeable and passionate about given back to their community. The scheme offers a holistic approach by matching patients with phone buddies with similarities between them and providing similar support to family and friends who are considering becoming living donors. This type of peer support is powerful and can help patients make informed treatment choices. Evidence has shown that

involvement of people from similar cultural backgrounds with relevant life and health experiences facilitates relationship building and cultivates empathy.

Transplantation as we know is the best treatment option for people with CKD; however, many black patients still have difficulty considering living donation as a choice. The phone buddies offer patients and their loved ones a sense of cultural identity and with their personal experience and understanding of living donation provide information, education, and tools they need to start the conversation. One of the real benefits of the scheme is that nurses and clinicians can seamlessly introduce the model of improvement to their black patients as part of their treatment plan.

### **Measurement Strategy:**

Outcome measures would include:

- Number and proportion of eligible recipients/participants referred to the scheme by clinical teams
- Number and proportion of eligible recipients/participants who engage with the intervention/ model of improvement.
- Number and proportion of potential living donors who engage with the intervention.
- Number and proportion of recipients/ participants who, having engaged with the intervention/model of improvement, proceed to talk with family and friends.
- Number and proportion of family and friends who, having talked with the recipient about living donation because of the intervention/model of improvement, offer to be assessed as a living kidney donor.
- Number and proportion of recipients/ participants and potential living donors who proceed to transplantation and donation.

**Qualitative analysis, to include** Recipient- and living donor-reported outcome and experience measures.

### **What we plan to do:**

The peer buddy scheme will form the framework for the model of improvement.

Working in collaboration with the renal team at Imperial Healthcare Trust we aim to test the model of improvement on a small scale by running a pilot with a group of black pre- dialysis patients willing to participate in the study. We want to test the idea that early conversations between black patients and black living donors/ recipients can significantly increase black patients' chances of receiving a pre-emptive transplant.

### **What are the objectives:**

- To develop a strategy for testing and implementing the pilot study that includes working in partnership with healthcare professionals and key stake holders.
- To work with clinicians to co-develop a referral system
- To set up a pilot study commencing January 2022
- To evaluate the study in December 2022

- If successful roll out the model of improvement across London January 2023
- Set up a working group with representation from collaborating organisations, staff reps from comms/ media and other relevant teams.