

PILOT

PROJECT REPORT 2024

Gift of Living Donation

Improving Equity of Access to Living Donation Kidney Transplantation for Black Kidney Patients



Peer Phone Buddies



Through their lived experience of living kidney donation, they have the unique opportunity to empower, educate, inspire Black patients. They take the complexity of living donation and explain it in a simple and practical way that gives hope.

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Abbreviations

CKD	Chronic kidney disease
ESKD	End stage kidney disease
GOLD	Gift of Living Donation
GSTT	Guy's and St Thomas' NHS Trust
HD	Haemodialysis
ICB	Integrated care board
KCH	King's College NHS Trust
KQIP	Kidney quality improvement programme, UK Kidney Association
LDKT	Living donor kidney transplant
LKN	London kidney network
NHS	National health service
NHSBT	NHS blood and transplant
PBS	Phone buddy scheme
PPB(s)	Phone buddy(ies)
QIP	Quality improvement project
RRT	Renal replacement therapy

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Community Foreword



Dr Dela Idowu

Founder Gift of Living Donation

Honorary doctorate, London South Bank University

Welcome to our collaborative Quality Improvement Pilot Project Report.

Health is a fundamental human right and our most valuable asset. We need to improve equity of access to living kidney donation and transplantation for Black kidney patients. End stage kidney disease is a life limiting illness that has a huge impact not only on a kidney patient's ability to work, study and socialise, but also their emotional and mental well-being. It also has a major effect on their families and relationships. Therefore, we must make kidney health a priority for underrepresented communities to reduce kidney health inequality and give individuals the chance to improve their health. We must work together to remove the barriers and find sustainable solutions.

Addressing health equity must be a top priority for commissioners, healthcare providers, stakeholders and healthcare trusts to deliver exceptional and excellent kidney healthcare. Investment is needed in programmes that will provide long term-health solutions and benefits. London is one of the most diverse multicultural cities in the world, yet it still faces large gaps in health inequalities, we must all do what we can to close the gaps. The need for health equity is great, but the impact it will have is far greater.

Gift of Living Donation (GOLD), which developed the pilot, believes that if we can improve equity of access to pre-emptive living donor kidney transplantation, it will help address many of the problems affecting kidney patients. These problems include low donation rates, higher death rates, large numbers of patients on dialysis for a substantial length of time and the number of patients that don't attend kidney appointments.

The Phone Buddy Scheme is the first tailored community peer-led intervention of its kind in London. It is a unique and new concept for a community intervention that provides Black African Caribbean patients the opportunity to speak with individuals from their community who have lived experience of living kidney donation at the start of their renal journey through a clinical referral process. The intervention offers a new approach to increasing the number of family members who come forward to offer living donations for Black kidney patients.

Living donation is a difficult and sensitive topic to discuss with family and friends within any community, however it is much more difficult and complex for Black patients due to ingrained cultural mindsets, taboos and myths about organ donation. It is for these reasons that Black patients would benefit from culturally tailored education about living donation when they first come to the clinic due to their need for a kidney transplantation.

The one-year pilot project featured in this report tested the introduction of a tailored community peer-led intervention at the start of the pre-emptive recipient pathway to change how we approach, discuss, and deliver living donation education and information to Black kidney patients.

A quality improvement project model focusing on health equity and community partnerships was integrated into the pilot project to offer a strategy to measure its value and impact on patient health outcomes. The pilot project aimed to review both the effectiveness of the phone buddy scheme and analyse the implementation and impact of the project on renal services. GOLD collaborated with Imperial College Renal and Transplant Centre, Guy's and St Thomas' (GSTT) Renal and Transplant Service and King's College Hospital Renal Department (King's Kidney Care) on the quality improvement project; this type of collaboration resulted in a successful partnership in addressing the barriers to transplantation in the Black community.

In this report, you will learn how the groundbreaking pilot project has reshaped the narrative of living donation in the Black community and demonstrated "proof of concept" that it is feasible to embed a cost-saving and sustainable tailored peer-led intervention in the pre-emptive recipient pathway. We genuinely believe this report will lay the groundwork and transform the landscape for a healthier and brighter future for Black kidney recipients, placing them at the heart of transplantation.

We are all proud of what we have achieved, the passion, commitment, and hard work will continue as we collaborate to bring hope to humanity as hope transforms lives.

Clinical Foreword

Frank JMF Dor, MD PhD FEBS (Hon) FRCS
Consultant Transplant, General and Dialysis Access Surgeon
Clinical Lead for Transplantation
Imperial College Renal and Transplant Centre



Living donor kidney transplantation is the preferred treatment option for people living with end-stage kidney disease. One of the many advantages of living donor kidney transplantation is the fact that it enables pre-emptive transplantation, which is associated with greater kidney transplant survival and better life expectancy compared to being transplanted after starting dialysis. Dialysis has a massive impact on quality of life for end-stage kidney disease patients due to the many associated health problems and the intrusive nature of the treatment. Hence, there is a huge incentive to avoid dialysis in end-stage kidney disease patients.

Unfortunately, in the UK, due to a complex interplay of several factors including cultural-religious factors, Black patients have less access to (pre-emptive) live donor kidney transplantation compared to white people. Therefore, there is a need to develop strategies to reduce this inequity of access to the best possible treatment for end-stage kidney disease patients in the Black community.

Gift of Living Donation (GOLD) has developed a community led intervention to address this inequity with their peer buddy phone support scheme. The initial experience with this scheme (funded by NHS Blood and Transplant's Community Grants Programme) has been described in this report.

The peer buddy support scheme has brought a bespoke solution for people with end-stage kidney disease in the Black community to increase awareness and uptake of living kidney donation and transplantation. The report describes the experience in collaboration with several London kidney units implementing the scheme in advanced kidney care clinics with the support of the London Kidney Network. It is an extremely powerful tool for Black patients and clinicians and very easy to implement. Patients have been supported by members of their own community that went through a similar process either as living kidney donors or as transplant recipients. The project has increased trust in healthcare professionals because GOLD and their peer buddies have literally partnered with clinicians and patients and worked together with the same goal in mind: to increase access to (pre-emptive) living donor kidney transplantation. Having conversations around the need for a kidney transplant and the need to discuss this in patients' social networks by people "who look the same and speak the same language" in addition to information by clinicians is an enormous step forward in the right direction.

The level of engagement described in the report by patients, peer buddies and healthcare professionals in a powerful triangular collaboration is amazing, and in my view forms the basis for expansion of this approach across the UK and across other ethnic communities facing lower rates of living donor kidney transplantation. I am convinced that community-based interventions will change the way Black patients discuss their illness and share their need for a kidney transplant—ideally from a living donor to avoid dialysis. Due to the simplicity of the peer buddy scheme and the patient satisfaction with the offered support, it empowers clinicians and patients to make pre-emptive living donor kidney transplantation the default option for end-stage kidney disease patients in their community which will remove disincentives based on misinformation around this topic.

Executive Summary

The One-Year Pilot Project (February 2023–February 2024)

This was a one-year quality improvement project (QIP) looking into the implementation and impact of a targeted community intervention on the renal replacement treatment choices of Black patients. We wanted to investigate if introducing a community intervention would bring about a behavioural change in the way patients considered their treatment options and discussed them with their family members. The vision and aim for this pilot project are to embed a tailored community-led intervention at the start of the pre-emptive recipient pathway and to scale up the model as a coordinated QIP across London to drive change, increase living donation rates and maximise living donation discussions. This was supported in part by the NHS Blood and Transplant (NHSBT) Community Grant Scheme for 2023-2024 and was unique in being the sole project integrating a community partnership directly with the NHS transplant work up pathway.

The QIP ran from February 2023 to February 2024, during which time GOLD had 180 peer-to-peer conversations with 149 Black kidney patients about living donation because of direct referral from clinical centres or self-referral following promotional events and materials. During the period of data collection, 11 potential donors contacted a living donor coordinator within one of the London centres for a potential recipient who had spoken to GOLD.

The QIP group deliberately chose to measure potential living donors presenting to a living donor coordinator as the measure of effectiveness during this twelve-month period. The intervention strives to increase access to pre-emptive living donor kidney transplant (LDKT) through routine, early culturally sensitive conversations to support potential recipients and donors, the end product of which is a family or friend feeling supported to engage with the living donor team. The primary goal was timely/early recognition of the need for a transplant for Black patients by multidisciplinary teams. The outcomes of the pilot project will be used as a framework for health services and professionals to better understand diverse communities to decipher some of the complexities around culture, race, religion etc. which will create a level of empathy instead of frustration that Black patients are not fully engaged in their care. We hope to encourage Integrated care boards (ICBs) to invest in community partnership programmes to reduce dialysis capacity and increase transplantation rates.

Our service model can be scaled-up and offered to other communities that are seldom heard or listened to in order to improve patient understanding about transplantation, including living donor transplantation from a cultural perspective in a timely and appropriate manner.

National Context

This report lands at a time when issues of inequalities for people of Black African Caribbean heritage have been brought to the forefront, and, in London, where the capacity within dialysis units are at a critical level.

A recent UK study showed that the rate of LDKT was 43.2% in White patients compared with 17.8% in Black patients ($p < 0.001$)¹ and the Kidney Research UK inequality report released in 2018 reported in the UK that people from Black and South Asian backgrounds are three to five times more likely to commence dialysis.²

The amount of space dialysis units have to provide the treatment for their population, is nearing capacity, and this situation is likely to worsen as our population grows and the rates of chronic kidney disease increase.³

Dialysis is expensive⁴ and when upfront costs of surgery are accounted for, transplantation is cheaper⁵ as well as associated with better clinical and quality of life outcomes.⁶ The proportion of patients on in-centre haemodialysis recorded as Black in the 2021 UK Kidney Association annual report⁷ was 26%, 44%, 47% for Imperial, GSTT and King's centres respectively.

Even when adjusted for the population demographics within London (13.5% reported as Black within London in the 2021 census⁸), this represents a huge over representation of Black patients on in-centre haemodialysis. This is of course multi-factorial, but we must ensure we have provided equitable, not just equal, access to pre-emptive living donation.

1 Khalil K, Brotherton A, Moore S, Evison F, Gallier S, Hodson J, Sharif A. Interaction between socioeconomic deprivation and ethnicity for likelihood of receiving living-donor kidney transplantation. *BMC nephrology*. 2022 Mar 19;23(1):113

2 Caskey F, Dreyer G, Evans K, Methven S, Scott J, Brettell A, Castledine C, Chapman F, Fraser S, Hounkpatin H, Hughes J. Kidney health inequalities in the United Kingdom: reflecting on the past, reducing in the future.

3 Kidney disease: A UK public health emergency the health economics of kidney disease to 2033, <https://www.kidneyresearchuk.org/about-us/influencing-change/health-economics-report/> accessed 10/6/2024

4 Pyart R, Evans KM, Steenkamp R, Casula A, Wong E, Magadi W, Medcalf J. The 21st UK Renal Registry annual report: a summary of analyses of adult data in 2017. *Nephron*. 2020 Jan 29;144(2):59-66.

5 Morris T, Maple H, Norton S, Chilcot J, Burnapp L, Draper H, Mamode N, McCrone P. Challenges and opportunities in the supply of living kidney donation in the UK National Health Service: an economic perspective. *Transplantation*. 2022 Nov 1;106(11):2137-42.

6 Tonelli M, Wiebe N, Knoll G, Bello A, Browne S, Jadhav D, Klarenbach S, Gill J. Systematic review: kidney transplantation compared with dialysis in clinically relevant outcomes. *American journal of transplantation*. 2011 Oct 1;11(10):2093-109.

7 UK Renal Registry, Annual Report Team. UK Renal Registry publishes its 24th annual report. *Journal of Kidney Care*. 2022 Sep 2;7(5):245-6.

8 Office for national statistics, regional ethnic diversity, census 2021, <https://www.ons.gov.uk/search?topics=9497> accessed 10/6/2024

A Blueprint for Community Partnerships

To tackle the disparity and work towards equity in LDKT we must understand the systemic barriers across healthcare trusts, healthcare professionals and communities; this will enable us to provide a future of co-production and collaborative partnerships to develop strategies to improve access to LDKT for all community groups. The pilot project will establish a blueprint for clinical and community QI by developing ways of working that allow activity across both sectors to be measured and improved iteratively.

This report shares our learning of a community-clinical framework to reduce inequity for Black patients in a specific part of the kidney care pathway; the combined expertise of GOLD and clinical teams across three diverse renal centres is key to this. There are also broader learnings here for how community organisations and clinical teams can work in a flat hierarchy to achieve shared aims with a clear framework.

London Kidney Network (LKN) Statement of Support

The GOLD peer buddy scheme is incredibly important because patients are at the heart of the initiative.

This unique collaboration between clinicians and the Black community is a catalyst for positive change and provides the space for real conversations which help clinicians learn about and understand the challenges faced by Black kidney patients.

Working in partnership with the GOLD team, the aim of the London Kidney Network has been to support a project that reduces inequality and variation across London by developing a successful, scalable and reproducible model of improvement.

This QI project aims to improve population health through better quality and outcomes, contributing to more equitable access to living donor kidney transplantation for Black patients, and ultimately an improved patient experience through reducing dependency on dialysis.

Stephen Cass
Director, LKN
Wendy Brown
Multi-professional Lead, LKN

Key Recommendations

This is a community intervention and QIP that is making a difference to a community that historically has very low donation rates. Renal managers, commissioners, and healthcare providers need to fund and invest in similar community partnerships and interventions now to have a long-term effect in five to ten years' time. We recommend:

1. A change to the current recipient pathway to include a tailored community intervention that offers most Black potential recipients timely and tailored community education on living donation
2. Clinicians to receive cultural awareness training and support to encourage discussions
3. Timely/early recognition of the need for a transplant for Black patients by multidisciplinary teams
4. Data integration at various levels into the current renal pathway to inform better health outcomes for Black patients
5. Co-produce a coordinated pan London QI strategy to promote "Transplant First"

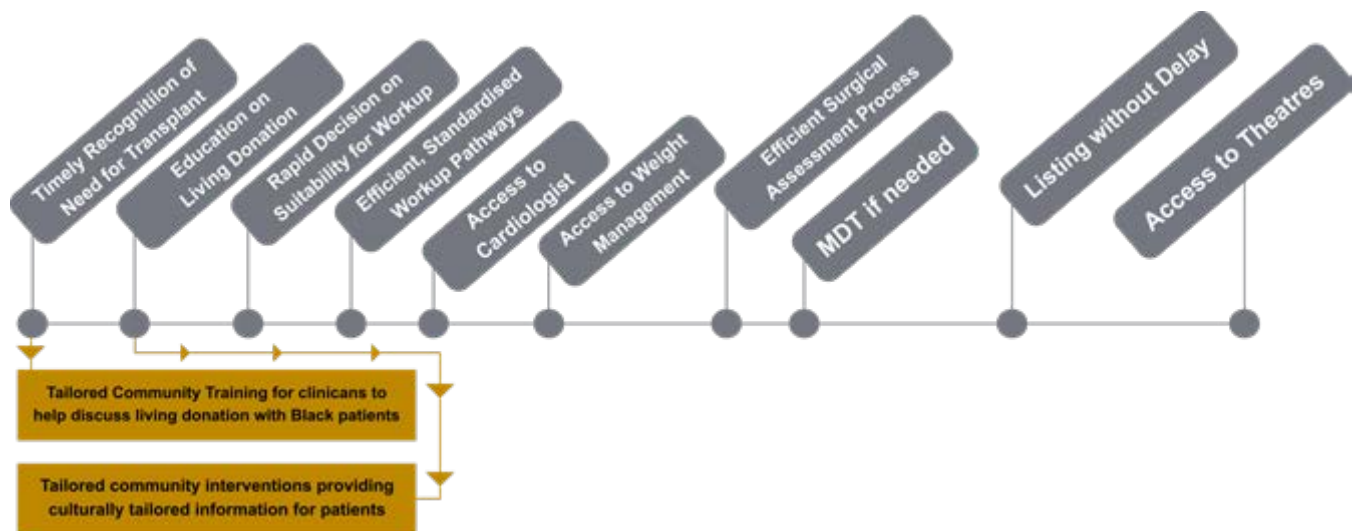


Figure 1: Community interventions offer solutions to the recipient pre-emptive pathway

Why London Needs This Now

The 2023 Kidney Research UK economic report, *Kidney Disease: A UK Public Health Emergency* reported that the direct cost of kidney disease to the NHS is £6.4 billion which equates to 3.2% of the NHS budget. The report identified four interventions to manage the economic burden of kidney disease of which one was increased rates of transplantation, specifically outreach and awareness to increase pre-emptive live donor transplants.

The difference between national and local ethnicity breakdown is stark; the need for this intervention is urgent in London and other similar urban areas. The result of this is an over-representation of Black populations on haemodialysis which highlights the need to improve equity of access to living donation and pre-emptive transplantation.

In 2023, the cost of dialysis for people with end-stage kidney disease was £1.05 billion annually, or 0.53% of the NHS budget. In addition to the direct cost of dialysis, transport for patients on in-centre dialysis costs approximately £225 million per year.

The cost to the NHS of dialysis to manage kidney disease (per person) is £34,000 per year. Kidney Research UK estimates £31.6m additional in-centre haemodialysis in 2030 and £167.2m cumulative for additional dialysis costs over ten years. The cost benefit of kidney transplantation compared to dialysis over a period of ten years (the median transplant survival time) is £241,000 or £24,100 per year for each year that the patient has a functioning transplanted kidney.⁹

An intervention that demonstrates any contribution to the pool of potential living donors for kidney transplants, especially for groups demonstrated to have lower odds of having a transplant, stands to make a significant contribution to cost reduction for the NHS.

Significant progress in living donor kidney transplantation (LDKT) has been made and Black African Caribbean recipients have benefited through increasing numbers of non-directed (altruistic) living donors and the UK Living Kidney Sharing Scheme over the last ten years, however, the disparity continues to remain in the uptake of living donation within Black and ethnic minority communities in the UK. Transplant activity 2022-2023 as reported by NHS Blood and Transplant (NHSBT) showed that, of living donor transplants taking place, thirty-two (4 percent) were to Black recipients and only nineteen (2 percent) were from donors of Black ethnicity.¹⁰

Between 2000 and 2022 at GSTT and referring centres (excluding forty patients with missing renal replacement modality at time of transplant):

- A total of 673 Black or mixed Black patients were transplanted, 2416 White patients were transplanted
- Only forty-four (6.5 per cent) of transplanted Black patients were done pre-emptively compared to 578 (24 per cent) of White recipients

Kerr M, Bray B, Medcalf J, O'Donoghue DJ, Matthews B. Estimating the financial cost of chronic kidney disease to the NHS in England. *Nephrology Dialysis Transplantation*. 2012 Oct 1;27(suppl_3): iii 73-80.
NHS blood and transplant, Annual activity report 2022 - 2023, <https://www.odt.nhs.uk/statisticsand-reports/annual-activity-report/>, accessed 10/6/2024.

- There were 128 (19 percent) transplants to Black patients were from a living donor compared to 1118 (46 percent) to White recipients

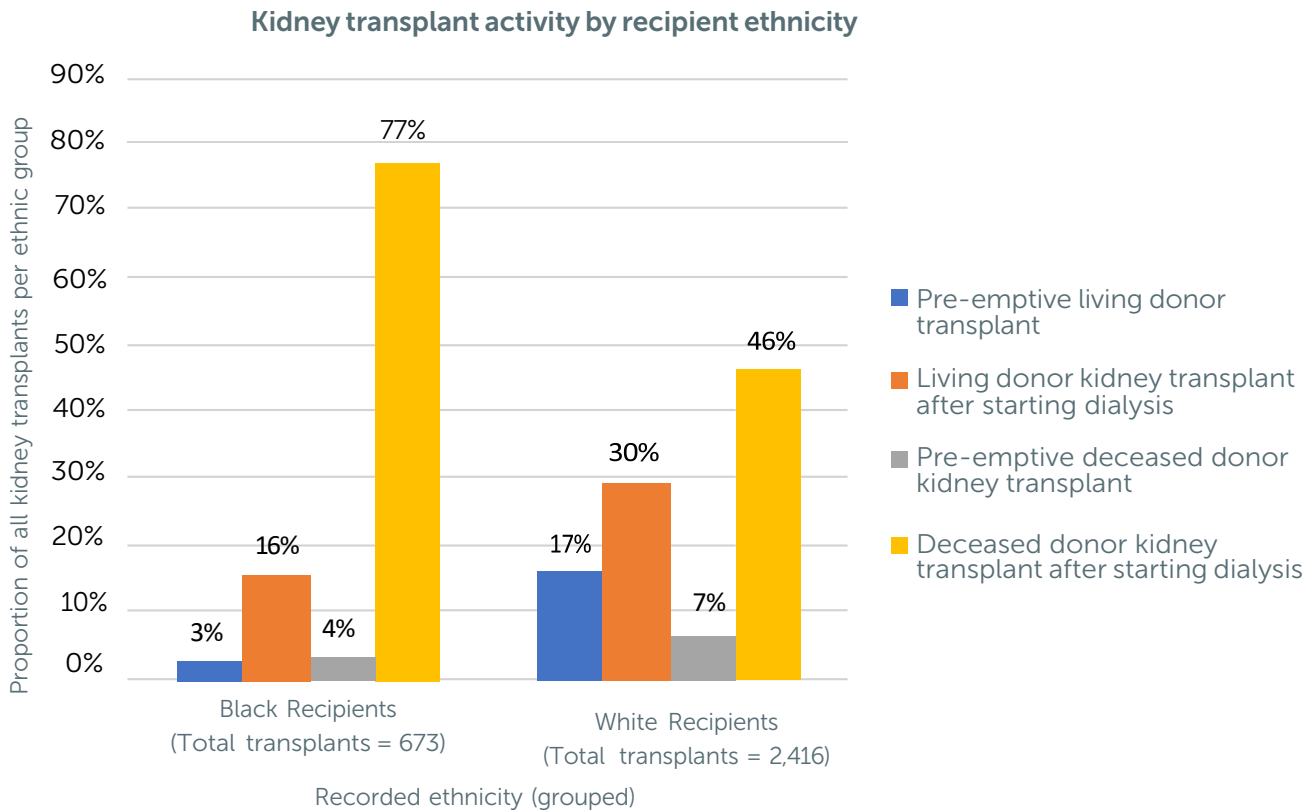


Figure 2: Local data from Guy's and St Thomas' showing transplant activity between 2000 and 2022 stratified by transplant type and recorded ethnicity of the transplant recipient

Improving Access to Living Donation

We are fortunate to serve a diverse population from all over the world, and it is one of the joys of working in South east London. Unfortunately, we are all too aware of the disadvantages Black and other minority ethnic groups face in different facets of the healthcare system, and this is especially so for those awaiting a transplant.

The GOLD buddy project is a fantastic initiative that has provided our patients an opportunity to explore living donation in a culturally sensitive way, and the feedback has been overwhelmingly positive. The patients really appreciate the chance to speak to someone who understands their racial and ethnic background and the impact this has on their access to living donor transplantation.

Ms Hannah Maple
Consultant in Transplant and Dialysis Access Surgery

Barriers to Pre-emptive Living Donor Transplantation for Black Patients

There are many barriers to living donation for Black kidney patients which prevent them from pursuing living donation. GOLD held a patient community educational event in April 2023 which was attended by patients with CKD, family and friends, healthcare professionals and phone buddies; these are some of the barriers identified at this event and throughout GOLD's work more generally.

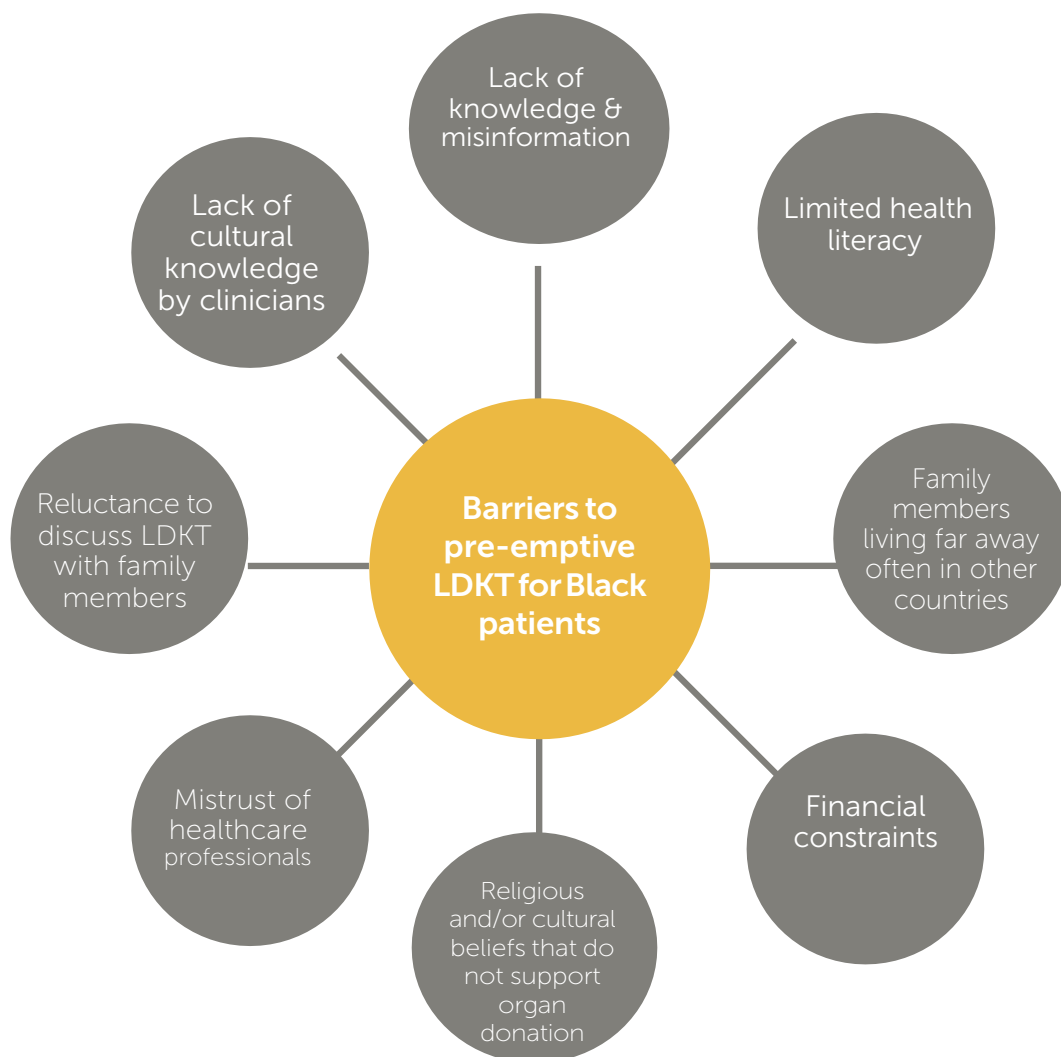


Figure 3: Barriers to pre-emptive LDKT for Black patients informed by GOLD community engagement work

The Value of Peer Support

It is important to develop practical solutions to address the barriers and inequity of access to kidney transplantation. Bailey et al. identify four variables as key mediators of the inequity in LDKT, presenting crucial targets to any intervention: patient activation, LDKT transplant knowledge, perceived social support and health literacy.¹¹ Culturally sensitive community-based interventions offer an important approach to addressing patient barriers and mediators of inequity.

There is solid evidence that community engagement interventions offering peer support have a positive impact on a range of health outcomes across various conditions including kidney disease. A systematic review by Longley. et al, (2023)¹² and Jain et al, (2018)¹³ argued that peer support has a powerful impact for ethnic minorities with chronic conditions. Indeed, within our pre-dialysis care pathway, peer support has helped patients reach decisions about treatment.¹⁴ The NHS Institute for Innovation and Improvement report (2008) Focus on: Preparing for End Stage Renal Disease stated that peers are a fundamental service component of high quality pre-dialysis care' and this is further championed by NICE¹⁵ advocating to 'direct people to other sources of information and support for example online resources, pre-dialysis classes and peer support'.

The GOLD Phone Buddy Scheme is a good example of targeted and tailored peer support for Black patients at the start of their kidney journey to support living donation discussions.

Perspective of Peer Support Movement

Peer support can be a uniquely valuable intervention for people living with kidney disease, particularly those whose needs standard health services fail to meet. However, it depends on clinicians to promote it and is only one of many tests and interventions which kidney clinicians have to remember to discuss.

We found focusing QI activity on a limited number of clinicians at a single specific point of the transplant pathway successful. This maximised the reach of potential patients offered peer support with changing the behaviour of only a minimum number of clinicians.

Eleri Wood
Kidney Nurse Consultant, King's College Hospital

11. Bailey PK, Caskey FJ, MacNeill S, Ashford R, Pryce L, Kayler L, Ben-Shlomo Y. Investigating strategies to improve Access to Kidney transplantation (the ASK trial): a protocol for a feasibility randomised controlled trial with parallel process evaluation. Pilot and Feasibility Studies. 2023 Jan 20;9(1):13.

12. Longley RM, Harnedy LE, Ghanime PM, Arroyo-Ariza D, Deary EC, Daskalakis E, Sadang KG, West J, Huffman JC, Celano CM, Amonoo HL. Peer support interventions in patients with kidney failure: A systematic review. Journal of Psychosomatic Research. 2023 May 20:111379. PAGE 50.

13. Jain Y, Jain P. Communitisation of healthcare: peer support groups for chronic disease care in rural India. BMI. 2018 Jan 10;360.

14. Hughes J, Wood E, Smith G. Exploring kidney patients' experiences of receiving individual peer support. Health Expectations. 2009 Dec;12(4):396-406.

15. Renal replacement therapy and conservative management, NICE guideline [NG107] Published: 03 October 2018, <https://www.nice.org.uk/guidance/ng107/chapter/recommendations>, accessed 10/6/2024.

Gift of Living Donation (GOLD)

Gift of Living Donation (GOLD) was formed by Dela Idowu, after coming forward as a potential living kidney donor for a family member. She saw the need to raise awareness and encourage more people from the Black community to talk about living kidney donation. The focus of GOLD is to improve access to living donation kidney transplantation for Black African Caribbean individuals with end-stage kidney disease. Their vision is to see as many as possible Black patients avoid the need for dialysis through pre-emptive transplantation. For more than seven years, GOLD has worked in collaboration with National Health Service Blood and Transplant (NHSBT) and stakeholders on community engagement projects.

Their work has led to increased awareness of the benefits of living donation—from the production of culturally tailored resources and information and hosting educational seminars, to creating the Black Living Donor Choir. The prevalence of kidney disease is increasing and there are numerous health inequalities, which means our work to develop sustainable solutions to address these problems is more important than ever. Collaborating with clinicians, researchers and peer volunteers with lived experience of living donation, the first pilot project to improve access to living donation for Black recipients through a clinical referral process and peer support was launched in London by GOLD in February 2023. This intervention will allow hundreds of Black patients living in London to have better access to renal transplantation, the best treatment outcome for end-stage kidney disease.

Addressing Health Equity

I would like to congratulate GOLD on launching the GOLD Phone Buddy Scheme, a community led intervention that has significantly improved equity of access to living donation for Black patients. It is a cost effective and sustainable solution and can be rolled out across London to help in breaking down the barriers to living kidney donation and increasing the survival chance of Black patients with chronic kidney disease.

Dr John Bolodeoku
Consultant chemical pathologist GOLD Trustee

A Tailored Community-led Intervention

THE GOLD PHONE BUDDY SCHEME



The Phone Buddy Scheme (PBS) is the first tailored community peer-led intervention of its kind in London to offer a practical and sustainable solution to increase the number of living donations for Black recipients. It is a unique and innovative intervention that provides Black African Caribbean patients the opportunity to speak with people from their community who have lived experience of living kidney donation at the start of their renal journey to shift cultural mindsets from Dialysis First to Transplant First.

One of the biggest barriers to LDKT for Black patients is the requirement that they ask someone in their family, or their network of loved ones or friends to be a living donor. One of the reasons why they don't ask is they often hear in their community that Black people don't donate.

Another barrier is many patients have little or no knowledge about living donation; it is difficult to ask someone to do something that you have no knowledge of. The GOLD Phone Buddy Scheme was co-created with Black patients, living donors, recipients and healthcare professionals and focuses on improving living donation conversations between patients and their family and friends to help encourage them to take the next step on their transplant journey.

How the Scheme Works

The referral process was developed to seamlessly fit into existing renal systems, processes and workforce to allow easy implementation into NHS clinical pathways.

A FIVE STAGE APPROACH

Stage 1. Referral

Patients are referred to the phone buddy scheme from various kidney clinics; information about referral to the PBS is usually given to patients when discussing treatment options. Clinicians must have patient consent before making the referral to GOLD. Alternatively, many patients self-refer either from seeing a poster, flyer, GOLD website or receiving an SMS message via Accurx (see page 36). An email referral is made with the name and phone number of the patient along with confirmation that consent for GOLD to contact them has been agreed.

Stage 2. Initial Assessment

GOLD contacts patients to gather background information, discuss living donation and offer conversations with a phone buddy.

Stage 3. Clinical Update

GOLD confirms receipt of referral and update clinicians about initial assessment with patient consent.

Stage 4A. Patient Matched with Phone Buddy

Phone buddy conversations may take place over six months; however, patients can be re-referred for further discussion thereafter. The frequency of the calls depends on the relationship between the phone buddy and the patient.

Stage 4B. Patient Declining Phone Buddy

Patients have monthly calls for six months so Buddy can offer support and check in whether anything has changed with regards to living donor conversations. It often takes Black patients longer to talk with family and friends.

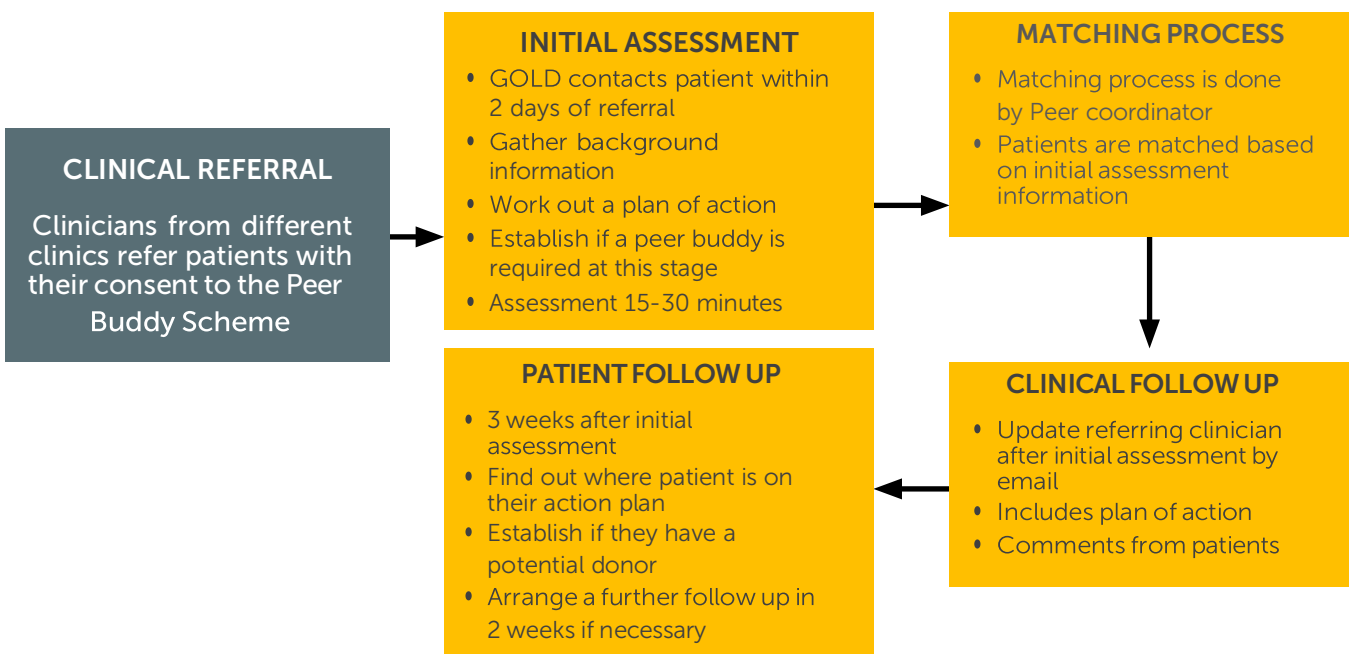


Figure 4: Process map of the GOLD phone buddy scheme from clinical referral to patient follow-up

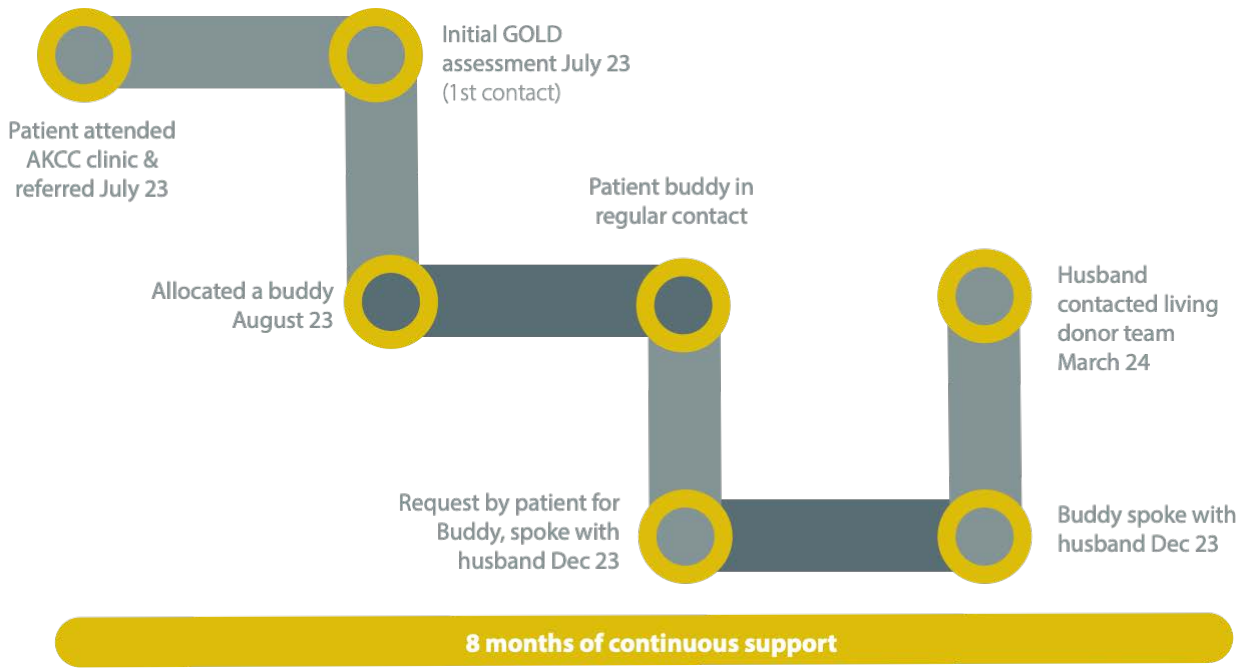


Figure 5: Example timeline of a patient participating in the GOLD phone buddy scheme

Key Aspects of the Peer Buddy Scheme

- Empower patients to shift cultural mindsets and demystify kidney donation
- Educate patients to facilitate timely conversations with family and friends
- Enable patients to be confident when speaking to family and friends by providing culturally relatable information and resources based in the community
- Encourage more family and friends to consider coming forward as a potential donor and
- raise awareness of the benefits of living donation

Benefits of the Intervention for Black Kidney Patients

- Provides a sense of cultural identity
- Feel less alone
- More confident on their renal journey
- Education at a level and in a language, they understand
- Help to navigate the cultural barriers
- Improved knowledge and understanding of living donation Culturally tailored information and support
- Feel part of a community
- More involved, engaged and open to other treatment options Helps with their overall emotional and mental well-being Provides renewed hope
- Understand the benefits of a pre-emptive transplant
- Develop a personal action plan for finding a living donor

THE GOLD PHONE BUDDIES

The GOLD Peer Phone Buddies (PPBs) are committed volunteers, they share their experiences of living donation to educate patients and potential donors on their kidney journey. They come from all over Africa and the Caribbean islands. For some, their heritage is second or third generation Black British whilst others are immigrants. Some of the PPBs have a faith background, whilst others have no faith at all. Their ages range from late twenties to sixties. The PPBs are in the UK, Nigeria and Ghana and have a wide range of lived experiences. Many of our phone buddies donated a kidney to loved ones and family members directly and others donated through the kidney sharing scheme. This wide variety of backgrounds and experiences means we can offer bespoke matching and cater to a diverse group of patients from different ethnic backgrounds.

Training

The PPBs receive peer mentoring training from a certified peer support mentor trainer, they also have transferable skills, such as culture, lived experience, scope of understanding, awareness of community and traditional beliefs, listening skills and empathy. The PPBs are not trained to give clinical or medical advice. After receiving training, they are matched with patients who are referred or self-referred to our peer support scheme.

The amount of time PPBs spend talking with their match varies on average between thirty minutes to an hour and usually takes place outside NHS working hours to make it more convenient for patients to talk outside their work hours in a space they feel comfortable (usually at home). The PPBs receive supervision and attend monthly virtual meetings via zoom and in turn offer support to the other PBSs from within the group.

Experiences of GOLD Phone Buddies

Told by Eric

I am a peer phone buddy and I have lived experience of living donation. I share the knowledge and experience I have gained to help people from my community navigate their kidney journey. I am aware some people living with kidney disease need empowerment, encouragement and support in talking with loved ones about living donation. I support Black patients who may be experiencing difficulties in discussing living donation, have no knowledge of the living donor process and have lots of questions!

My lived experience is very valuable, my donor story is very moving and for some patients I have spoken with it's a game changer in their attitude towards living donation. I am part of a community and I enjoy helping others to break down the barriers and stigma of organ donation in the Black Community. But more importantly, being a phone buddy gives me the opportunity to give back to my community, raise awareness of the benefits of living donation and give people hope again.

Told by Derricka

One of the benefits of being a phone buddy is that I don't only get to share my story of living donation, but I also listen to patients' stories. I hear why it is so difficult for many of them to ask friends and family for a kidney, I listen to their fears and concerns and in some cases hear how guilty they feel when a loved one has offered to donate. I offer tips and suggestions that can empower them to start the conversation of living donation with their family and friends. The regular contact with my buddy match is very helpful as they often ask questions they can't ask their nurse or consultant. I sometimes signpost them to other services if they need additional support. I love sharing in their joy and excitement when a potential donor has come forward. Being a phone buddy allows me to connect with my community and impact lives. It's a privilege being with a patient at the start of their kidney journey, and as one of my buddy matches said "it is a journey of hope"

From Community-led Initiative to Collaborative QI in the NHS

Embedding community initiatives into the complex structure of the NHS in a sustainable way is difficult and inaccessible to a community organisation without an inside partner. A QIP was a way for both sides to collaborate and evaluate the impact of integrating a community intervention into the clinical transplant pathway. The QIP was formally registered at the participating three sites across London: Imperial, GSTT and King's.

Informed by the King's Improvement Science framework,¹⁶ QIP proposal was co-written by a diverse collection of stakeholders including GOLD, consultant transplant surgeons and nephrologists, renal registrars with data experience, advanced kidney care practitioners, the London Kidney Network (LKN, NHS England funded body) and patient representatives.

⁹ King's Improvement Science resources, <https://kingsimprovementscience.org/resources/>, accessed 10/6/2024

Aims and Objectives of the QIP

Aim

To increase the number of potential living donors for Black kidney patients presenting to living donor coordinators.

Objectives

Implement a referral to GOLD for all patients who are Black, have significant kidney disease (eGFR<25ml/min/1.73m²) and are considered potentially eligible for kidney transplantation in three renal units across London.

1. To improve departmental understanding:
 - To produce local departmental metrics of the current population eligible for pre-emptive living donor transplant and current rates of living donor transplants stratified by ethnicity
 - Improve departmental understanding of inequity within services and cultural attitudes to living donation
 - Improve understanding of living donation within Black communities
2. To establish multi-disciplinary working groups at Imperial, King's and GSTT sites to facilitate and embed opportunities to offer the phone buddy scheme
 - Process map patient journey within services
 - Identify key members and opportunities for referral
3. To encourage referral to the phone peer buddy scheme:
 - In appropriate settings through promotion and education events
 - Initially referrals will be more targeted (e.g. specific clinic/pathway/clinician) and then all eligible patients will be offered phone buddy support
4. To measure the implementation, effectiveness and acceptability of the intervention:
 - To share learnings and scale up successful practice

Designing and Implementing the QIP

We used process mapping and plan, do, study, act (PDSA) cycles to commence the project. Each site made a process map of the journey for a kidney patient to assess who would be best placed to start the implementation of routinely offering Black kidney patients the support of a GOLD phone buddy. Process mapping allowed a considered and concentrated effort to embed routine referral; PDSA cycles were then used to iteratively improve how the routine offering of the referral to GOLD was implemented.



Figure 6: PDSA model used in the GOLD QIP

Leadership and Coordination



Core Team – Dela Idowu (GOLD Founder), Wendy Brown
Multi-professional Lead, (LKN), Frank Dor (Imperial Transplant Surgeon)



Clinical Working teams at Guy's, King's and Imperial – MDT expert teams in
AKCC and/or transplant who engage and refer eligible patients



Data team – Renal registrars with data analysis experience who
collate data, aiming to minimise workload for clinical teams



GOLD team - Peer Phone Buddies with lived experience of living kidney
donation who empower, share and engage with Black kidney patients
to support conversations with potential donors

Figure 7: Structure of the GOLD QI team

Renal registrars (middle grade doctors) are required to participate in quality improvement as part of their training so building this role at each site as a fixture to collate data on a quarterly basis is a sustainable way to build the QI within a busy renal department. They are also well placed to liaise with the clinical team, in particular living donor teams and advanced kidney care clinics. The clinical teams are fully embedded and provide a sustainable way of offering referral to eligible patients.

Choosing Evaluation Metrics

This QIP aimed to measure a simple intervention for a complex problem and to demonstrate worth within routine systems. Measures were carefully identified to capture activity and improvement; for example, an increase in potential presenting donors can be influenced by the phone buddy scheme and captures an increase in trust within Black kidney patients which may not be captured if we measured the number of living donor transplants. It also means we can capture activity without the time delay of waiting for a living donor transplant (may take years for a kidney patient with an eGFR of 25ml/min/1.73m²) and not miss an increase in presenting donors for Black kidney patients who may turn out not to be a suitable match (presentation is still increasing the opportunity of living donor transplant for these patients).

NHS Information Governance

Forming a collaborative QIP meant observing clinical and site-specific governance structures. Formal registration of the QIP at each local site ensured oversight and endorsement within each Trust. Additionally, there were discussions with key departmental stakeholders at each site which was important to be able to implement the PBS. This was also embedded alongside routine clinical service as part of monthly transplant and advanced kidney care governance meetings.

A phone-based intervention means there are less stringent rules than in person or onsite patient engagement with a community organisation. This is also key for the service to be agile to patient demand and patient schedules.

The separation of the data team within the clinical system and GOLD was necessary from an information governance perspective. This information was then collated and conveyed as a total number of presenting potential living donors to ensure anonymity and prevent sharing of clinical information outside the NHS.

The use of the Accurx platform to provide secure SMS messages to patients was already approved by local governance teams for patient appointment reminders; the use of the platform for targeted signposting to the PBS for all eligible patients within the service was agreed upon locally. The sent messages went through a patient advisory and governance process via GSTT.

GOLD donor and recipient volunteers are recruited and inducted via GOLD's process, they are DBS checked and have safeguarding training. All GOLD's policies, guidance and procedures are developed in line with Trust Governance requirements for the OIP.

As part of the collaboration there were agreed standards and guidelines used for recordkeeping and data entry. The development of documentation relating to PBS includes patient and volunteer consent forms, application forms, volunteer agreement, session feedback form.

Joining in the National Conversation

The Kidney Quality Improvement Partnership (KQIP), which is part of the UK Kidney Association, has a Transplant First campaign uniting many QIPs looking to address the need for pre-emptive transplantation in the UK. Developing the GOLD QIP has allowed participation in this discussion as well as access to QI resources for GOLD as a community organisation. A pan-London QI strategy to improve pre-emptive transplantation could be the catalyst to improving living donation rates among underrepresented communities and changing cultural mindsets.

KQIP Statement of Support

Health inequalities in access to pre-emptive transplantation in the Black community are well known, contributing to longer wait times for transplant and reliance on dialysis to maintain life. Similar problems are seen in other under-represented groups, closely linked to social deprivation.

Renal units working with KQIP on “Transplant First” QI projects report ongoing challenges in engaging the Black community with the concept and reality of living kidney donation. The GOLD initiative offers real hope by showing the effectiveness of a simple, well-designed intervention.

Key success factors are co-design and co-production by healthcare professionals and people from the Black community with lived experience of kidney disease. Renal registrars have gained real insight into successful use of QI methodology and the possibilities created by community collaboration. Careful use of QI methodology and metrics to detect early indicators of improvement clearly show the benefits of the project for the Black community and the wider NHS. This maximises the opportunities for sustainable funding to allow more people to benefit from timely peer buddy support and living donation.

With appropriate funding, the model could be expanded and adapted to allow people across the UK to benefit from a community collaborative approach.

The GOLD initiative was presented at the KQIP Transplant First webinar in November 2023 and the learning will be incorporated into the KQIP Transplant First project report later in 2024. We look forward to inviting the GOLD team to update the kidney community at future KQIP events to maximise learning opportunities and benefits for patients.

A New Era of Community Partnerships

This QIP addresses a specific point of inequity within both a disease process and a specific health service, but more broadly this project looks to establish a framework for a community organisation and healthcare team working together as equal partners. Establishing a clear structure where clinical and community leaders collaborate on decision making, have clear boundaries around information governance, share meeting chairing and have impact measures which are relevant to both partners have been key points to making this work. These learnings are scalable for other QI projects looking to reduce inequity in other parts of the journey for kidney patients or even for other disease processes.

There must be a recognition and valued appreciation that community organisations provide a reach and agility not possible within the NHS structure and system that need long-term sustainable funding. The strategy of implementing the PBS using a QIP framework moves it beyond a well-meaning voluntary service to a programme that can be integrated into the national renal strategy for transplantation allowing outputs and impact to be communicated in a language understood by clinicians, commissioners and managers. If we are serious about addressing health equity, the limited dialysis capacity and delivering better kidney health we must give community organisations the investment opportunity needed to transform and save lives.

Community partnerships are integral to community-based health promotion and intervention models, they are essential for improving health equity and health outcomes for an entire community. The NHS and stakeholders such as the London Kidney Network Transplant Workstream are migrating to partnerships with community organisations to co-create their five-year plan to improve health equity in transplantation in targeted communities.

LKN Transplant Work Stream Statement of Support

One of the key aims of the LKN is to co-create a five-year plan for transplantation that will help to improve rates of organ donation, especially in underrepresented groups. We are looking forward to the new opportunity to form community partnerships and collaborate with charities and community-based groups such as GOLD to move the dial in health equity in transplantation.

We are meeting with charities and patient groups to understand the barriers faced when considering transplantation, the impact of end stage kidney disease on patients and their communities and how we can work together to address these issues.

Co-Chairs

Lisa Silas, Advanced Nurse Practitioner Guys and St Thomas' NHS Foundation Trust

Sapna Shah Consultant Nephrologist – King's College Hospital NHS Foundation Trust

Ismail Mohamed Consultant Surgeon – Barts Health NHS Trust

It is also paramount for sustainable funding that these partnerships can demonstrate their value (financial and other); this is often difficult with complex interventions which look to change culture and/or reduce inequality, which is entrenched, but it is essential to be able to evaluate performance with merit.

This pilot project has provided us the opportunity to co-develop a successful blueprint that allows everyone to come to the table as equal partners. It has allowed us to address topics such as governance, cultural knowledge, different languages and perspectives, to speak openly about systemic racism and race and its impact on health equity and public health.

We have seen the success of community partnerships and the value it has added to patients. This is the way forward, quality improvement models with financial support for community transformation.

Public health and more recently primary care (through the formation of integrated care systems) have more established ways of working with community organisations than secondary or tertiary care centres (such as those within this QIP). NHS England has made clear recommendations for working in partnership with people and communities¹⁷ by establishing ten principles for working with people and communities; we believe the GOLD QIP covers all of these principles with respect to pre-emptive living donation.

Inspire Black Health Statement of Support

At Inspire, our mission is to enhance the health and wellbeing of Black Londoners through dedicated support, empowerment, and community engagement. Recognising the unique challenges faced by Black communities, we strive to bridge health disparities and foster a culture of health equity. We wholeheartedly support the work of Gift of Living donation (GOLD), their community intervention is a vital initiative aimed at addressing the significant disparities in organ donation within Black communities.

This intervention is a crucial step towards ensuring equitable access to life-saving transplants and improving health outcomes for Black individuals in need of a kidney transplant.

We are committed to collaborating with GOLD and other stakeholders to create a more inclusive and effective organ donation system. Together, we can make a profound difference in the lives of individuals and families within the Black community, fostering a future where everyone has equal access to the gift of life.

<https://www.inspireblackhealth.london/>

¹⁰ NHS England, working in partnership with people and communities: statutory guidance, July 2022, <https://www.england.nhs.uk/publication/working-in-partnership-with-people-and-communities-statutory-guidance/>, accessed 10/6/2024

The ten principles for working with people and communities from the NHS England Working in partnership with people and communities: Statutory Guidance October 2022¹⁸

1. Centre decision-making and governance around the voices of people and communities
2. Involve people and communities at every stage and provide feedback to them
3. about how it has influenced activities and decisions
4. Understand your community's needs, experiences, ideas and aspirations for
5. health and care, using engagement to find out if change is working
6. Build relationships based on trust, especially with marginalised groups and those affected by health inequalities
7. Work with Healthwatch and the voluntary, community and social enterprise sector
8. Provide clear and accessible public information
9. Use community-centred approaches that empower people and communities, making connections to what works already
10. Have a range of ways for people and communities to take part in health and care services
11. Tackle system priorities and service reconfiguration in partnership with people
12. and communities
13. Learn from what works and build on the assets of all health and care partners – networks, relationships and activity in local places.

¹¹ NHS England, Working in partnership with people and communities: statutory guidance, July 2022, <https://www.england.nhs.uk/publication/working-in-partnership-with-people-and-communities-statutory-guidance/>, accessed 10/6/2024

HIDDEN-CKD Project

For individuals diagnosed with End-Stage Kidney Disease (ESKD), Kidney Transplantation is the optimal treatment of choice, however there is a need to focus on preventing ESKD especially in the Black community where a high proportion of people are undiagnosed. Prevention means stopping problems from arising in the first place. The HIDDEN-CKD project launched in 2022, is an initiative that provides community kidney screening and identifies early onset of kidney disease to reduce kidney health inequalities within the ethnic community in South east London.

The initiative led by King's, was an opportunity to go into the Black community with a team of peer educators to provide basic health and kidney health checks. Since the project launch over 1,500 people have taken part, we also referred over 150 hundred people for follow-up investigations with their GP.

Eight people with early-stage and three with late-stage chronic kidney disease (CKD) were also identified through this important initiative. These people received follow up care and advise on how best manage their kidney health. The initiative empowered individuals to self-manage thereby reducing their risk of kidney disease. The prevention work of Hidden CKD will help reduce the number of Black patients being diagnosed with ESKD and needing a transplant. Community interventions and partnerships such as the Hidden CKD project and the GOLD QIP offer long term solutions for better health.

Roseline Agyekum Community Nurse
Senior Practitioner Lecturer, King's College London

Pilot Evaluation

We evaluated the project in three parts.

1. Implementation

What proportion of Black kidney patients potentially suitable for kidney transplantation were referred to GOLD during the QIP?

2. Effectiveness

- Are phone buddy conversations associated with an increase in presenting potential living donors for Black kidney patients?
- Is there a better understanding of the inequality for Black kidney patients accessing pre-emptive living donation within clinical teams?
- Is there a better understanding of living donation and kidney transplantation amongst Black kidney patients?

3. Acceptability

Is the phone buddy scheme acceptable to patients and clinical teams?

For the evaluation, data from the clinical team (e.g. stage of renal failure, presentation of potential donor), data from the GOLD team (e.g. length of conversations, success in contacting, matching with buddies) and responses to anonymous surveys for both staff and patients were collected.

Implementation

How well did we implement the GOLD phone buddy scheme into three renal centres?

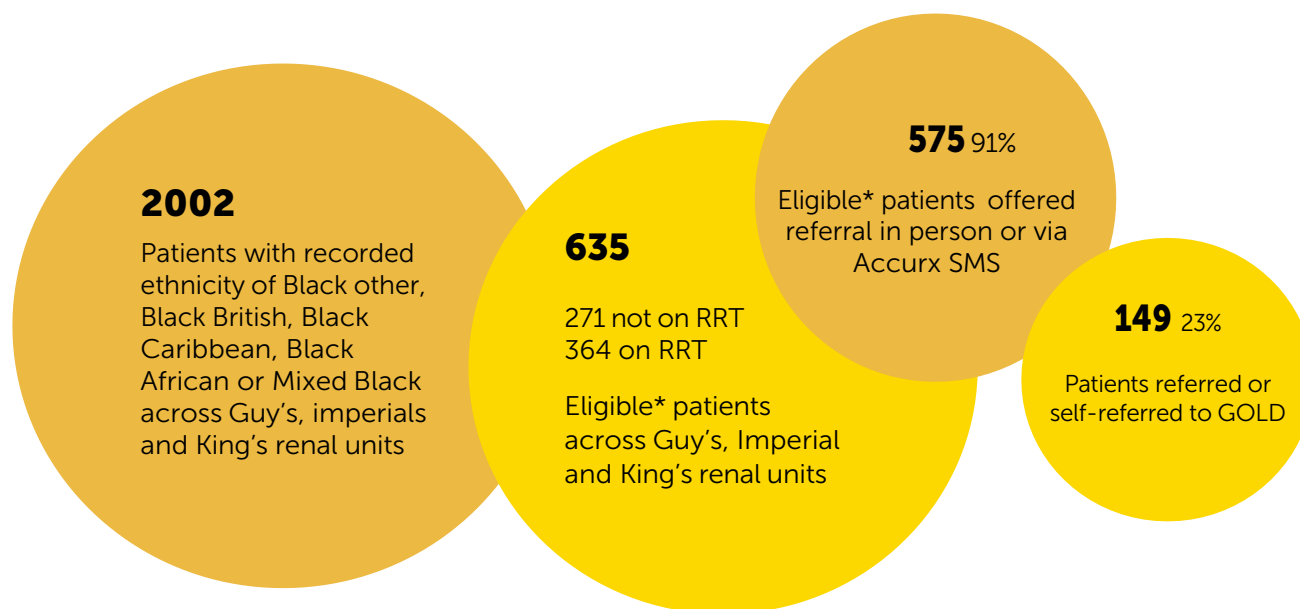
One of the biggest challenges in quality improvement is creating the change to measure, especially in busy hospital departments. Implementation refers to the process of integrating the GOLD phone buddy scheme into routine practice— where every eligible patient would be offered a referral (or the opportunity to self-refer) to the scheme across the three renal departments.

The GOLD QIP team used multiple methods to maximise opportunities for eligible patients to contact the phone buddy scheme, including:

- Clinician education events: organised webinars, local department presentations, presentation at an advanced kidney care symposium
- Resource sharing: large posters in waiting rooms, booklets, flyers, website, videos, podcasts
- Patient community education events: events for kidney patients and their family and friends to meet and talk with the phone buddies

- SMS messages to eligible patients signposting to the service: messages were co-written by phone buddies/patient advocates and the QIP team and reviewed by clinical departments. They were sent via a batch messaging service provided by Accurx.

The data team at each clinical site identified patients eligible for referral to GOLD at the start of the QIP (February 2023) through searching electronic records, and when this was not possible, through publicly available data (UKKA annual report).



*Recorded ethnicity of Black other, Black British, Black Caribbean, Black African or Mixed Black, under 70 years old with no clear contraindication to transplantation and eGFR $\leq 25\text{ml}/\text{min}/1.73\text{m}^2$

Figure 8: Breakdown of patient numbers to measure implementation of the GOLD phone buddy scheme (Black patients under the three services in the QIP > patients eligible for referral to GOLD > Patients offered referral > patients actively referred or self-referring to GOLD)

This enabled identification of 2002 patients with a recorded Black or mixed Black ethnicity. After applying the broad inclusion criteria, notes review indicated if patients were not suitable for referral for other reasons. For example, if they were not entitled to NHS care or waiting for home office approval, whether they had made a choice to not be selected for transplant work up or were on a conservative care pathway. There were several reasons why not all eligible patients were offered a referral during the pilot period. This may have been due to prioritisation of referral of pre-RRT patients, not having contact details or SMS bouncing back, patients not attending clinic appointments during the pilot project year, not being seen by a clinician who was familiar and confident to refer to GOLD or dying or receiving a deceased donor transplant before they could be offered a referral. We aimed to approach patients with eGFR $< 25\text{ml}/\text{min}/\text{m}^2$ focusing on selection for pre-emptive transplantation to enable sufficient time for conversations with potential living donors to take place.

Patient Referrals

One of the major barriers to implementation was accurate recording of ethnicity data and a real time representation of patients in the advanced kidney care clinics which represents pre dialysis patients. Another limitation is that patients may only be seen two to four times a year while their kidney function is at higher levels which offers only limited occasions to invite a referral to GOLD in person.

Alternatively, patients may not attend hospital appointments or see a clinician that considered GOLD referral during the appointment. One approach to ensure equity of access and that all potential eligible patients were offered the opportunity to be referred, was to use direct SMS messaging.

Consequently, we partnered with Accurx who kindly offered a free trial of batch SMS messaging, where we were able to sign post self-referral, in this way promoting autonomous engagement and self-advocacy. Using the text messaging meant the pilot project was not reliant on the clinician seeing the patient to refer.

The text messages offered the patient more time to consider participating and the information was not overwhelming since it was not delivered at the same time as a clinical conversation about their kidney health. Since not everyone uses SMS, the text message was constructed in a way that it was possible to read on a non-smart phone.

Furthermore, the website URL for feedback and opt out was shortened so it could be typed out on a PC/laptop. Wording of the message was evaluated first by the phone buddies, trialled with the Camberwell Kidney patients' associations at King's College and GSTT, staff within kidney care nursing and the patient safety management team. In order that patients felt confident this was a genuine SMS— it came from an NHS sender: and signed off with 'Guy's/Kings/Imperial Kidney Team'. This contained no patient identifiable information. Repeated text messages offered reminders and prompts for patients. Batch messaging ensures consistency of offering and offers the patient the option to sign up to community events. The patients had the option to complete the opt out questionnaire.

Effectiveness

Are phone buddy conversations associated with an increase in potential living donors for Black kidney patients?

This is a simple community led intervention for a complex problem; as a proxy to measure the equity of access to living donor kidney transplant for Black patients, we have measured the number of potential donors coming forward for these patients. There are two main limits to this: firstly, it only shows an association between speaking to the phone buddies and having a presenting donor and secondly it may take years for a potential donor to present so the impact of the phone buddy scheme is likely to be under-represented.

Patients may have indicated a potential donor to GOLD who is yet to contact the living donor coordinator; although this does not reach the threshold of a potential donor coming forward, it may demonstrate the time lag associated with discussions and the reality of living donor work up commencing. This was evidenced in the pilot since two further potential donors contacted the LD team after the official end to the pilot.

This wholly emphasises the need for even earlier referral for patients. Whilst many factors influence whether living donor transplantation goes ahead, our long- term aim is to increase these rates in the Black community, acknowledging shifts in behaviour and culture take time.

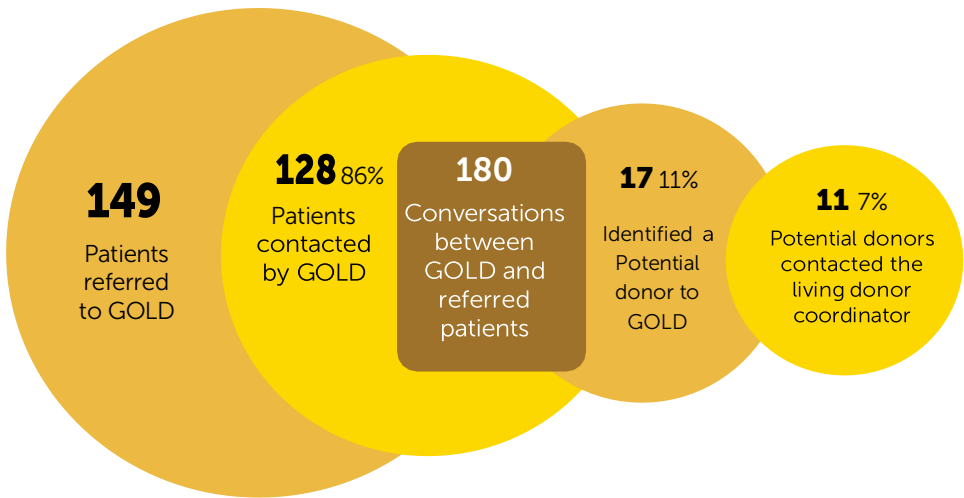


Figure 9: Activity occurring for those referred to the GOLD phone buddy scheme (Patients referred > Patients successfully contact > conversations taking place > patients who identified a potential donor to GOLD > patients who identified a potential donor who went on to contact the living donor co-ordinator within their transplant site)

Patient Demographics

During the one-year QIP, 149 patients were referred to the scheme of which the majority were female (65 percent), of African ethnicity (62 percent) and aged between 50-69 years (52 percent)

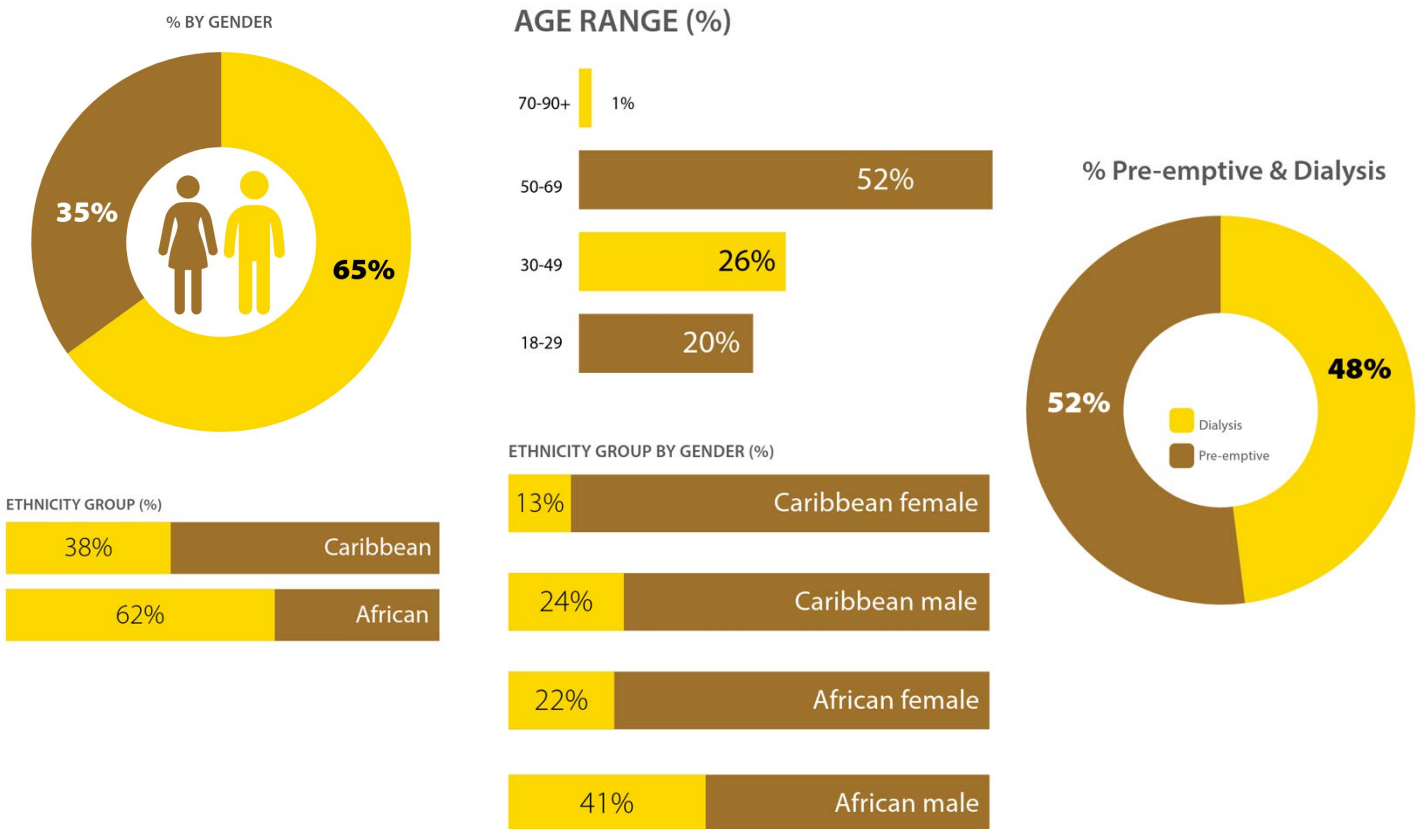


Figure 10: Demographics of patients referred to GOLD

Scaling Up

The figures above demonstrate the intensity required to get from identifying Black kidney patients within renal services, to identifying whether they are eligible for GOLD referral (no clear contraindications to transplantation), reaching out to offer referral, GOLD making contact, supported discussions with family and friends leading for some to a potential donor coming forward.

By capturing data over a period of twelve months, the QIP gives services and commissioners a sense of what impact and value the GOLD phone buddy scheme can have within a service in a period of one year. It is likely that a higher proportion of people speaking to GOLD will have potential donors come forward when observed over a longer period. The broader implementation of the scheme, the more referrals and thus the more supported presentation of potential donors for Black patients.

Putting a narrative around the numbers, a Case Study

Patient "A" age fifty-two is of Nigerian heritage who lives with his wife in Southeast London. They have three adult children who reside in Lagos. Patient "A" was diagnosed with end-stage renal disease in 2023. He has not told his family of his illness as he is the patriarch and holds strong ties to his culture and the need to maintain his dignity as the head of the family. He works full-time as a college teacher, but he was finding it increasingly difficult to do everyday tasks due to increasing ongoing tiredness. He had no support from his family regarding his ongoing tiredness as they were unaware. He had an eGFR of 10 percent. Living donation had been mentioned when discussing his treatment options, however it was not an option he considered since he had a huge mistrust of the healthcare system and healthcare professionals, hence had started looking at the different types of dialysis.

During a subsequent appointment, Patient "A" was informed about the Phone Buddy Scheme and asked if he would like to speak to someone from his community who had experienced living donation. He immediately said yes.

An initial assessment and discussion with the GOLD team resulted in matching the patient with a trained phone buddy from his community. The patient and buddy looked at some of the cultural reasons which prevented him from considering living donation. The phone buddy shared his experience, and the patient was able to identify with him. The phone buddy suggested some tips on how he can initiate the conversation with his family. The patient mentioned that talking with his buddy was like talking with a friend, he could talk openly about his fears and concerns, something he never would have done with a healthcare professional. The buddy scheme provided him with the confidence he needed to initiate a conversation with his family about his kidney failure and living donation. The conversation with his family resulted in his wife coming forward as a potential donor, unfortunately due to her high blood pressure she was not a suitable match. One of the children is now looking into the process of donation and has already contacted the main transplant centre in Lagos.

If patient "A" had not been referred, he never would have considered Living Donor Kidney Transplantation (LDKT), and although he has started haemodialysis, due to this declined eGFR, he and the family still want to opt for LDKT, this may help him avoid spending three to five years on dialysis.

Peer led community interventions like the phone buddy scheme can be an effective way of promoting health equity and addressing many of the cultural barriers people from the Black community experience towards living donation.

Is there a better understanding of Living Donation amongst Black kidney patients?

The scheme has improved the knowledge, education and understanding of living donation for so many Black patients who were referred, they have gained the confidence and feel empowered to speak to family and friends.

Many patients cited that they understood living donation and transplantation much more from speaking to their living donor phone buddy who was from the same community than their clinician who was often white. This created a connection, a level of empathy, and a feeling that they are understood. There are so many additional benefits the scheme has to offer Black patients, one of the most important ones is the sense of cultural identity, this is something they rarely experience from their renal clinicians and as a result, don't often take in what is being discussed about living donation and therefore don't pursue it. However, when speaking with a Black person, there is that sense of community and patients will often be more open to discuss and pursue living donation.

We established a service evaluation questionnaire to understand more about the patient experience and what might have changed for patients following their discussions with GOLD. The questionnaire was again devised via the support and expertise of the phone buddies, GSTT and King's Kidney patient association, as well as the patient experience team at GSTT and then it was reviewed by Dr Pippa Bailey, Consultant Nephrologist at Southmead Hospital who is a national lead on living donor acceptability research.

There were thirty-five responses from the 128 patients that spoke to a member of the GOLD team following referral (27.3 percent response rate). Invitation to complete the GOLD participant feedback form was sent via email contact from GOLD and a patient and phone buddy approved SMS delivered by Accurx.

From the thirty-five responses to the patient survey of those that had spoken to GOLD, twelve had spoken to friends or family prior to GOLD referral vs. twenty-three that had not.

- 71.4 percent felt that interacting with GOLD had changed the way they discuss living donation and kidney transplantation with friends and family.
- 91.4 percent felt that their level of confidence to discuss living donation with potential donors had increased, with 68.6 percent (twenty-four out of thirty-five) now being able to discuss it with family and friends.
- 97 percent of participants felt it was valuable to speak to members of the Black community, with 68.5 percent saying this was 'extremely valuable'.
- 54 percent felt that the information received was extremely specific to their own personal culture, whereas 14.3 percent felt that it was not.
- 80 percent of responders felt that in talking to GOLD their views on kidney transplantation, living donation and kidney health had changed more generally.

Thirty-four out of thirty-five patients would recommend speaking to GOLD to another patient. Recurring themes centred around feeling better informed and that they were empowered to have better communication with loved ones. Also, that GOLD offers a space where culture is valued, and patients feel supported.

What Patients told us

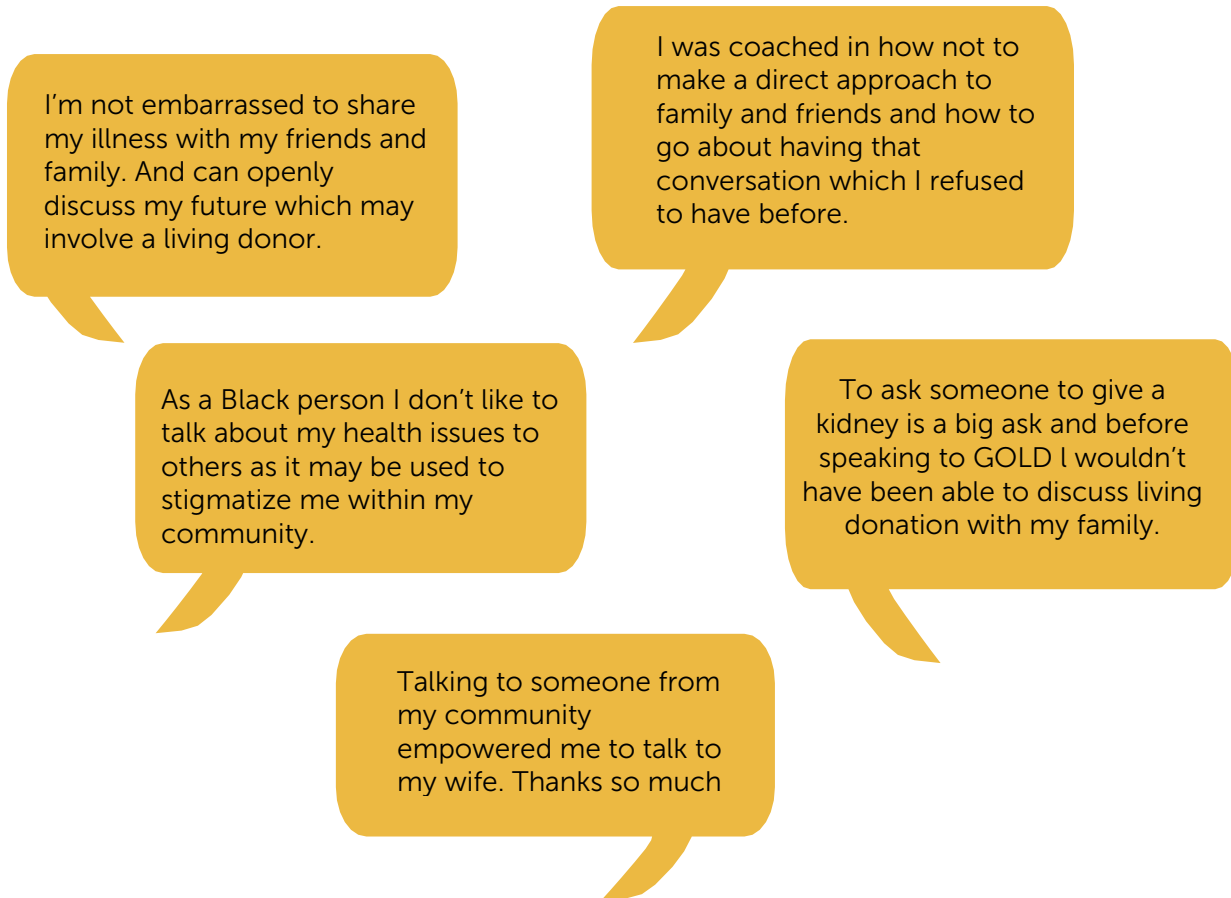


Figure 11: Quotes from patients participating in the GOLD phone buddy scheme reflecting on their experience

There was greater understanding after talking to GOLD that living donation provides the best option for kidney replacement. When asked what GOLD offers that is different than their clinical team— patients felt the information was more in depth and offered a lived experience from patients who understand how culture affects their health decisions, they experienced greater trust and encouragement and felt more confident. To feel better supported patients stated that they wanted to speak to GOLD earlier in their patient journey to aid conversations with their family members, as well as hearing and seeing patients and recipients that have gone through living donation.

Acceptability

The fact that 86 percent of the patients referred to GOLD then spoke to a member of the GOLD team shows a high uptake in this intervention. It is understandable that patients may feel obligated to accept a referral when it was offered in person in a clinic even though they did not want to participate or may later change their mind. Further views on acceptability were garnered from the service user questionnaire.

Alongside this evaluation, we felt it was crucial to hear from patients that were declining the opportunity to speak to GOLD and gain understanding as to what the underlying reasons might be to guide future work. Following up from the Accurx SMS signposting self-referral to GOLD, an option to opt out from further SMS communication was offered to patients as well as an opportunity to give feedback as to why they were declining, with emphasis that this would not affect their clinical care. Five patients chose to decline in this way and a further fourteen

declined referrals by phone or face to face citing the following reasons.



Figure 12: Reasons patients gave for not participating in the GOLD phone buddy scheme

In this way we sought to give voice to reasons for non-participation as well as those patients accepting referrals, which will enable further nuanced interventions in the future.

Future Opportunities

Further work can be done to gain a better understanding about why living donor transplantation is not being considered more broadly. The team can consider referral to the phone buddy scheme even earlier in the patient's renal journey, so dialysis is not considered the default option. In addition, there can be further development of culturally specific resources based on patient feedback.

Qualitative Themes

We took comments from over one hundred patients during their initial assessment and recognised six common themes.

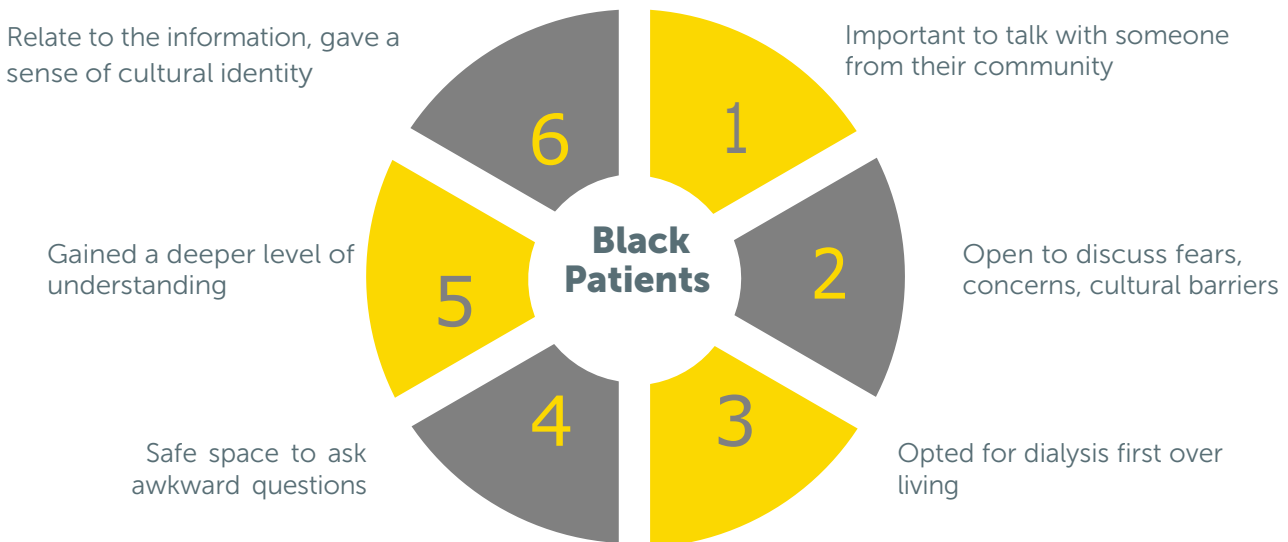


Figure 13: Themes identified by GOLD during engagement with over 100 patients

Healthcare Professional Feedback Questionnaire

As part of the evaluation and effectiveness of implementing a community-led intervention in the recipient pathway, we asked clinicians from across the three transplant centres who implemented the intervention for their feedback based on the six questions below.

1. Why do you feel the QIP is needed?
2. How easy was it to implement the referral scheme? Did you face any challenges?
3. Has QIP changed the way you discuss LDKT with Black patients?
4. What have been the impact/ benefits/ value of the QIP for you and your Black patients?
5. What have been the learnings/ successes?
6. Your recommendations

Their feedback has been summarised in the six themes below.



Figure 14: Themes from feedback from clinicians who participated in the GOLD QIP

Value of the QIP for Clinicians

OLIVIA FERRES, NURSE SPECIALIST ADVANCED KIDNEY CARE TEAM, IMPERIAL COLLEGE HEALTHCARE NHS TRUST

I find the GOLD project to be an extremely important contribution to the service provided for Black patients I see in the clinic. It is a scary time for anyone going through renal failure but the ability to speak to someone from the Black community that has lived experience is very valuable. This provides reassurance and support for these members of our community. I think supporting patients in the community will help to give the patients the confidence to explore live donation and to open-up difficult conversations with the people close to them.

I have found this referral scheme to be very easy and straightforward. Once I learned the process and how easy it was, I embraced this service and what it provides to my patients. I am encouraged by the feedback I receive from the GOLD team once contact has been made.

I believe this has changed the way I speak to patients about LDKT as sometimes I felt we had hit a block in the road, but now I think that this service enables the conversation to be ongoing. There is hope that we can look deeper into the possibilities of live donation by giving the patients (and myself) the confidence to take more steps in that direction.

Referral to GOLD is now a natural part of my discussions with Black patients when discussing transplantation.

I feel that this service is only starting and has a great deal more to contribute to support patients with live donation. I am excited to work with the GOLD team and Dela. This is groundbreaking work, and more resources should be allocated so that this great work can be spread wider and reach more people. Every Black person that is suitable for transplant should be referred to this programme as part of their work up to increase discussions around transplantation and engagement with live donation.

Value of the QIP for patients

PATIENT STATEMENT: MR B

My wife would never have come forward as a potential living donor if I had not been referred to the GOLD phone buddy scheme. During one of my early hospital appointments when I was recently diagnosed with ESRD, I saw one of clinicians who was not empathetic and had no understanding of how difficult it is for Black recipients to speak about living donation. The doctor said, "I am not surprised that you don't have a living donor, most Black patients don't and end up spending a lifetime on dialysis." I left the hospital that day feeling dehumanised and traumatised and vowed never to go back and I did not for six months. I was so upset that I felt what was the point of living if I was going to spend a lifetime on dialysis.

Months later I was contacted by one of the nurses to come in for a routine blood test, whilst taking my blood, she started talking to me about living donation, I almost shouted at her! But she was understanding and asked if I would like to speak with someone from my community who was a living donor for support and more information. I immediately said yes. She referred me to the GOLD team, where I spoke to people from my community about living donation. They encouraged me to talk with my wife, and by then I was mentally prepared. I talked to my wife who surprisingly said yes, she would donate one of her kidneys. We are still going through the assessment process but no matter the outcome my life changed at the point I was introduced

to the phone buddy scheme; my buddy gave me the hope I never had.

Key Learnings from the GOLD QIP

- A quality improvement methodology was key to being able to respond to data and reshape the intervention (for example, the location of key referral opportunities)
- The complexity of race, cultural knowledge, the value of lived donor experience and the need for a peer led community intervention in the pre-emptive recipient pathway
- The need for more cultural awareness training for renal clinicians for them to feel more confident to discuss living donation with Black patients
- Shifting cultural mindsets to accept living donation as a treatment option can take years
- The demographics and location of patients influenced their decision to consider living donation. Patients from African heritage were more likely to decline living donation on the grounds of cultural beliefs and religion than patients from a Caribbean heritage.
- Recording of ethnicity data is key to being able to offer tailored care
- Accessibility to local data for renal patients' needs to be improved to allow agile QIP by trainees
- Being clear about what success looks like for both the community and clinical partners was key and informed the metrics used for the project

Limitations of the Project

- Low questionnaire uptake rate
- Accessibility of data for the data team and availability of ethnicity data (located in the NHS)
- This is a unique approach and unfamiliar concept; took time to embed
- Unforeseen referral delays due to doctors' strike
- Some delays due to identifying referral clinicians at the start of the project
- Difficult to identify relevant indicators to correlate with poor questionnaire uptake
- Patients not wanting to be contacted despite providing their consent
- Underlying health problems for Black patients such as Apol1 testing, hypertension, diabetes
- Slow response (patients)
- Slow assessment process for overseas donors (they found it very frustrating with a lack of a sense of urgency from clinicians)

Wider Pilot Engagement

As a team we have sought opportunities to share and discuss this project regionally, nationally and internationally through several avenues.

- Poster presentations at national and international meetings (British Transplantation Society (BTS) Conference 2023, 2024; European Society for Organ Transplantation (ESOT) 2023; UK Kidney Week (UKKW) 2023 and American Transplant Congress (ATC) 2024, Black Health Inequalities Summit in London 2024; South West and East Kidney Society (SWEKS) 2023
- Oral presentation at Advanced Kidney Care Symposium hosted by King's College London (KCL)
- Oral presentation at Transplant first seminar for UK Kidney Association (UKKA, KQIP)
- Article about pilot study to appear in Kidney Matters magazine June 2024
- Webinar entitled 'Towards Equity in Living Donation: Empowering Teams for Change' was initiated and funded by Chiesi Limited in partnership with GOLD
- King's Star Award's 2023
- GSTT in house magazine GIST to feature an article in their July edition on the benefits of the scheme to GSTT Black kidney patients

Recommendations

The findings in this report have informed the following recommendations for improving equity of access to living kidney donation

1. A change to the current recipient pathway to include a tailored community intervention embedded to offer Black potential recipients timely tailored community education on living donation
2. Clinicians to receive cultural awareness training and support to encourage discussions
3. Timely/early recognition of the need for a transplant for Black patients by multidisciplinary teams
4. Data integration at various levels into the current renal pathway to inform better health outcomes for Black patients
5. Co-produce a coordinated pan London QI strategy to promote 'Transplant First' using the GOLD QIP toolkit
6. The provision of culturally, accessible information available in a variety of formats for patients
7. Consider having a living donor leader/champion in advanced kidney care for each renal unit
8. Include a statement at every clinic appointment regarding consideration of transplantation work up and ask the patient if they have talked with any potential living donors, and if so, if there are any potential suitable donors
9. Collection and audit of both pre-renal replacement and dialysis patients' demographics with accurate recording of patient's ethnicity data, especially for those with missing information
10. Embed a prompt for referral to GOLD into NHS clinical electronic patient records for eligible patients to ensure parity of referrals. Tailored living donation information to be offered to Black patients on dialysis to facilitate discussions.

Conclusion

We are confident that the impact of the collective evidence described in this pilot project will lead to a substantial and sustainable improvement in equity of access to living donation and transplantation for Black kidney patients living in London.

Throughout the one-year period of the pilot project, the implementation of the tailored community intervention in the recipient pathway, led by renal clinicians and community peer phone buddies, empowered Black patients to discuss living donation with family and friends. The qualitative metrics show these conversations contributed to a small increase in the number of Black patients with a presenting potential donor, this will have a significant impact on transplantation and patient health outcomes now and in the future.

We know transplantation is a cost-effective intervention when compared with the high cost of treatments such as renal dialysis, we also know that London has a high proportion of Black patients on renal dialysis, it is for this reason that this community led intervention has the potential to support the coming forward of many more potential Black donors.

We do not have the evidence from this pilot to make informed projections, however, the evidence is clear, this pilot demonstrates 'proof of concept'— that it is feasible to set up a cost effective, sustainable community intervention model that will have a ripple effect five to ten years from now.

The quality improvement model which was the framework for the pilot project will be shared with the NHS, healthcare trusts, and stakeholders such as the London Kidney Network and KQIP as part of the London Kidney Network's five-year Transplant plan for London. This will allow us to co-create a London strategy and agree upon annual activity targets to reduce the dialysis capacity for Black patients needing dialysis and increase pre-emptive donation rates. Measures for this strategy will be guided by health outcomes for patients, number of presenting potential living donors and improved rates of pre-emptive transplantation.

Kidney disease is on the rise globally and will have huge implications for people from underrepresented communities. We must therefore look to the future and envisage a London with a reduced dialysis capacity and a culture of Transplant First Dialysis Second. However, this can only be successfully achieved through work with collaborative partnerships and substantial investment.

For more information about this report visit: www.giftoflivingdonation.co.uk
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