

# Knowledge Exchange Event Community Link Workers

## Peer Educator Project

**Bushra Riaz BSc MSc**  
**Policy lead (Scotland)**



- The leading charity committed to developing treatments, patient information and raising vital public awareness to help save lives.
- Over the past 60 years, our research has made an impact. Every year an estimated 60,000+ people with kidney failure are alive today because of the advances in research that we have directly contributed to.
- Research that we've funded is making significant progress in keeping retrieved kidneys viable for longer, which would mean less kidneys go to waste, and more are available for transplant.

# Kidney Research 2023

- 6.4 million pounds funding awarded for research in 2020/21!
- 14 new projects !
- [Research - Kidney Research UK](#)



Visit our research grants page to find out about our current funding calls.

<a href="#">Hybrid grants round awards: November 2022</a>	+
<a href="#">Polycystic Kidney Disease Research Awards: March 2022</a>	+
<a href="#">Paediatric Research Project and Innovation Research Awards: March 2022</a>	+
<a href="#">Kidney Research UK-Stoneygate Research Awards: March 2022</a>	+
<a href="#">Research and Innovation Research Awards: November 2021 and January 2022</a>	+
<a href="#">Fellowship awards: March/April 2021</a>	+

## Research news



Looking for new markers of kidney rejection in children to support personalised care

3 March 2023

[Read More](#)



Research to improve our understanding of polycystic kidney disease and discover new treatments

3 March 2023

[Read More](#)



Looking to return to research?

2 March 2023

[Read More](#)



A force for good

£150k kidney research funding awarded to Wales

1 March 2023

[Read More](#)

# Research Grants



[Research grants - Kidney Research UK](#)

## What is a research grant?

Kidney Research UK grants are funds made available to scientists and healthcare professionals to answer or investigate a particular question, or to support their training within kidney research. This process usually occurs twice each year.

Researchers apply through a formal process, including expert scientific and patient review of their proposed projects. If a researcher is successful, they must keep Kidney Research UK updated on their progress and share their final results. We also offer additional advice and support to help researchers maximise the impact of their discoveries, including making future treatments available to patients or helping with further development of their projects.

Through the generosity of our supporters we are able to make projects like these happen.

# Successful research through KRUK 😊

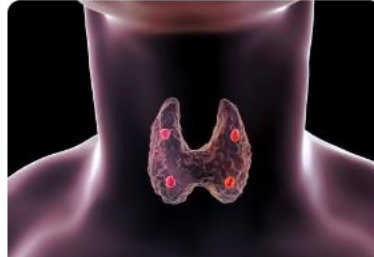
## Research news highlights

Read about the latest life-saving research we're funding.



Understanding the impact of the Covid-19 pandemic on kidney patient care

25 May 2023



The search for a new way to keep bone and blood vessels healthy in chronic kidney disease patients

22 May 2023



Identifying and managing mental health problems in kidney disease patients. Can we do better?

2 May 2023



Research gives new hope to patients with idiopathic nephrotic syndrome

18 April 2023

### Kidney blood type changed in 'game changing' first by University of Cambridge researchers

ANGLIA | HEALTH | SCIENCE | UNIVERSITY OF CAMBRIDGE | Monday 15 August 2022 at 4:04pm



### Researchers change blood type of kidney in transplant breakthrough

University of Cambridge team's work could significantly increase supply of organs for people with rarer blood types



# Kidney disease

- Kidney disease is a silent killer. There are over three million people in the UK with it right now and there is no cure.
- **Kidney failure is up to 5 times** more common in people from the Black, Asian and minority ethnic communities.(EMG)
- Asian people with **diabetes are 10 times** more likely to get kidney failure than white people with diabetes
- **Diabetes and high blood pressure** are 2 major causes of kidney disease.



# Function of Kidneys

## Make Urine



Remove waste products from blood into urine

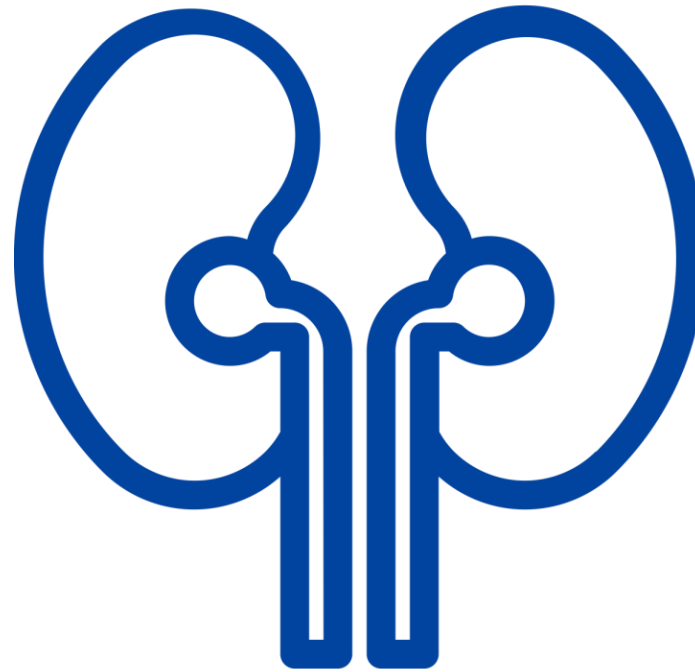


Regulates salt & water

## Activate Vitamin D



Keep bones healthy



**Kidney** Research UK

## Clean your blood



Remove drugs

## Produce hormones



Produce erythropoietin



Regulate BP



Diabetes

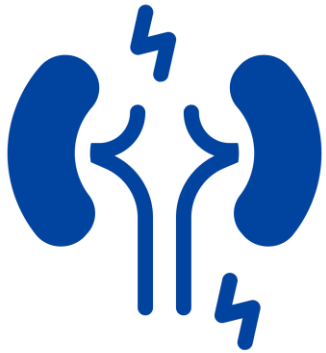


HBP



CV Disease

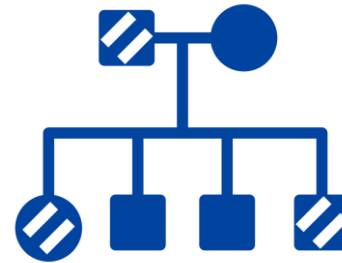
# Causes of Kidney Disease



Inflammation



Drugs



Inherited kidney disease



Blockages



# Importance of Kidney Health

Patients with kidney disease at significant risk of CV events



10 x >



Premature death up to 10 x more likely than need for dialysis



High Risk of heart attacks and strokes

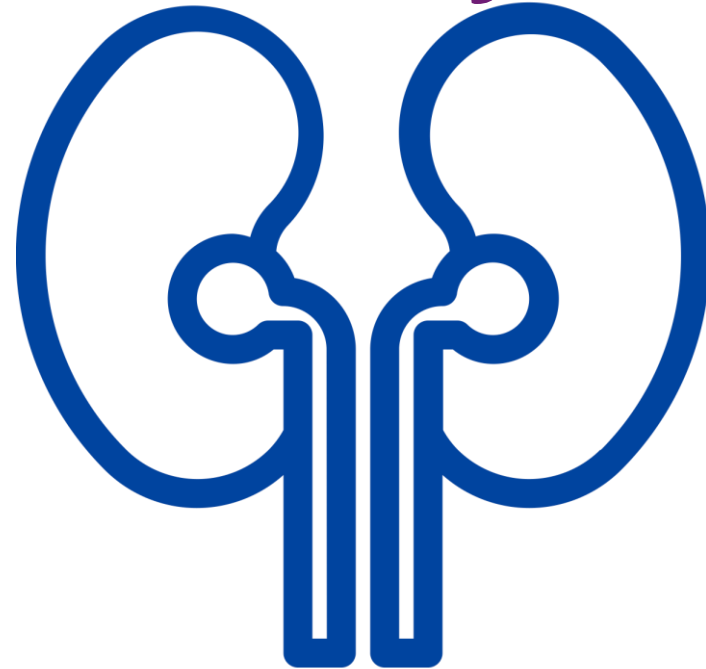


CV death accounts for 40-50% of deaths in patients with stage 4 & 5 CKD



50% of patients with Stage 4 & 5 CKD have cardiovascular disease

# How to keep kidneys healthy



# How is Chronic Kidney Disease diagnosed?

Kidney Research UK



Blood Test



Urine Test

Stage of Chronic Kidney Disease	Description	e-GFR Level
One	Kidney function remains normal but urine findings suggest kidney disease	90 ml/min or more
Two	Slightly reduced kidney function with urine findings suggesting kidney disease	60 to 89 ml/min
Three	Moderately reduced kidney function	30 to 59 ml/min
Four	Severely reduced kidney function	15 to 29 ml/min
Five	Very severe or end-stage kidney failure	Less than 15 ml/min or on dialysis

# Treatment of CKD

Treat underlying cause



Control BP



Diabetes Control



CV risk reduction

If progressing- Supportive care or prepare for transplant/ dialysis



Kidney Transplant



Haemodialysis



Peritoneal dialysis

# Organ and Tissue Donation.

Don't leave your  
loved ones in doubt.



ORGAN  
DONATION  
SCOTLAND  
Scottish  
Government



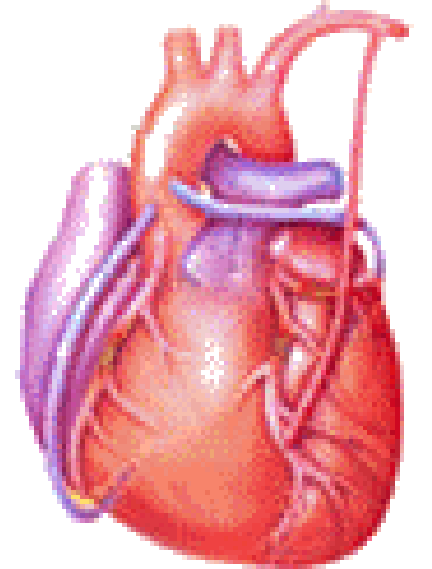
# What is organ and tissue donation?





## Which organs can be donated?

- Heart (valves)
- Lungs (2)
- Kidneys (2)
- Liver (2)
- Pancreas
- Small bowel
- Eyes



# Deceased and Living Donation

- Donation after brainstem death ( by neurological criteria)
- Donation after circulatory death
  
- Living – donate kidney to loved one or altruistic



# An appeal – an opportunity to help at no cost to ourselves

Donation is community action – by saying yes and sharing that information with our loved ones , we can save up to 9 lives and give sight to a couple and transform a few others



# The process

- Doctors will always do their best to save the lives of patients
- Unfortunately either due to a serious accident or an unrevivable brain haemorrhage or stroke, doctors have to accept futility
- They will then along with the Specialist Nurse approach the family
- The family will be asked for consent regardless of whether patient is on the organ donor register.
- The Specialist Nurse will guide the family through the process
- Many tests will be done and personal information will be sought.
- The patient will be cared for just the same by the ICU team until the time for donation happens
- This will depend on the arrival of the regional surgical team but the Specialist Nurse will keep the family updated

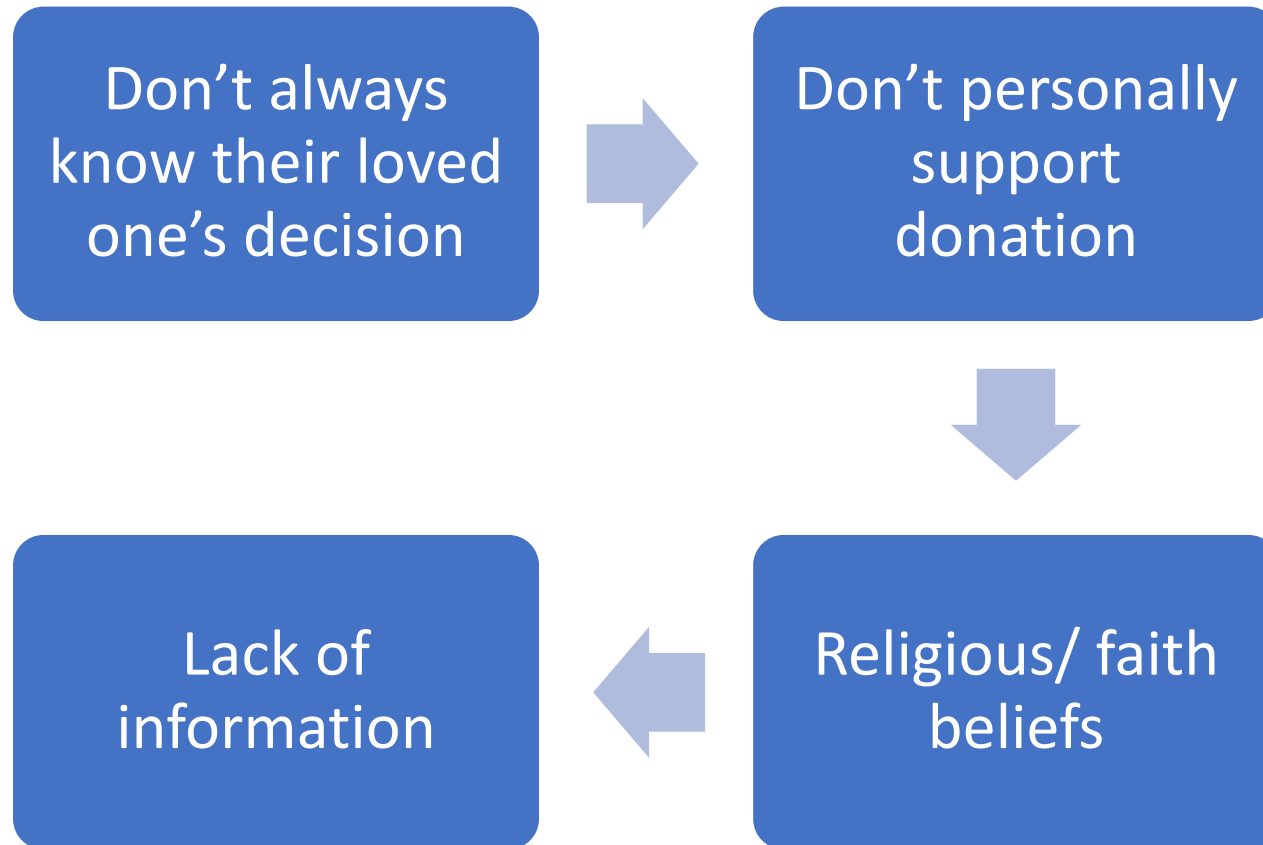


# The process

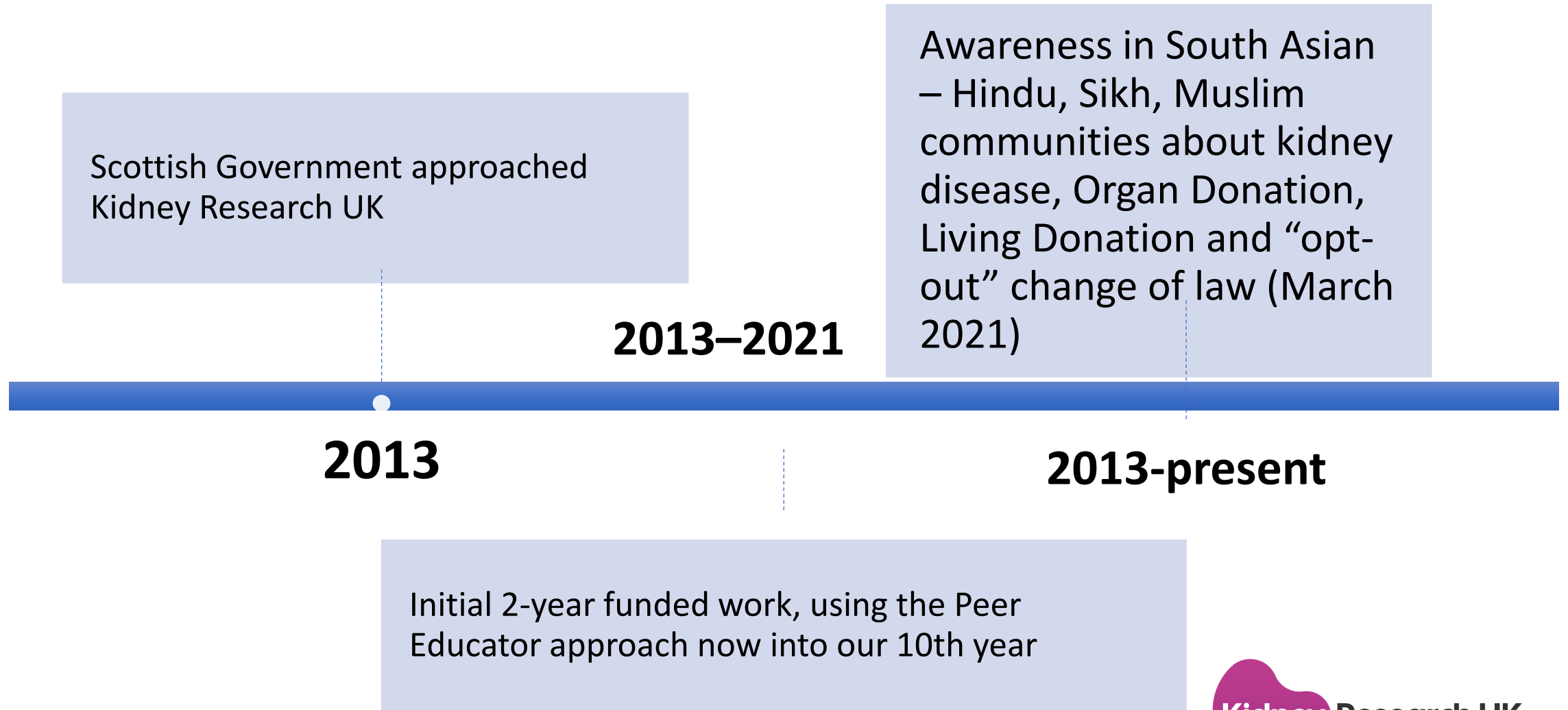


- The family can stay with the patient until its time to go to theatre
- Spiritual/religious help will be offered
- The family can decide whether to go or stay once patient goes to theatre
- The patient is looked after by an anaesthetic and surgical team
- The operation is done as respectfully as any other operation
- Any religious considerations will be adhered to
- The family will be given an opportunity to say goodbye once the operation is done

# Why Do Families Refuse?



# Scottish peer educator project



# Project Needs

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Scotland- Asian, African, Caribbean or Black, Mixed or Other ethnic groups - 4%

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2.7% of Scotland's population identified as Asian, Asian Scottish or Asian British (latest Census – updated August 2021)

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Registration onto the (NHS) Organ Donation Register (ODR) from the ethnic minority group (EMG) communities was low.

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Unaware of health issues – Diabetes and High BP common in SA communities leading causes of kidney failure and the importance of Organ Donation

# Project needs cont..

- More likely to need a transplant, less likely to donate and more likely to wait longer for a donation.
- Misinformation –operations guidelines, myths of mutilations etc.
- Cultural and religious misconceptions and lack of knowledge
- Language barriers
- No “link” for community members to ask questions about Organ Donation



# Peer educator impact

- Engaged with over 9000+ people
- Over 1250+ sign onto NHS OD Register
  - **1 donor can save up to 9 lives**
- More awareness and discussion is taking place
- Enquires and discussions
- Scottish Project most successful in UK !
- Multi Award Winning Success : Impact on Health – CEMVO, Scottish Asian Business Awards.





## Results

Now in its  
**9th**  
year of  
funding

Volunteers have  
participated in

**over  
180 events**

Engaged with

**10,341 people**

**Signed over  
1,150 people** to the  
NHS ODR

With one person saving up to

**nine lives!**

This has resulted in  
positive outcomes  
and discussions  
within communities.



# Further awareness

- NHS Blood and Transplant Updated resources
- Scottish Government OD website updated
- Speaking to MSPs and government/parliamentarians – policy on CKD
- Schools presentations
- Updated resources – bilingual (OD videos)
- Online resources – social media awareness
- Webinars (During pandemic and ongoing)
- Attending conferences –networking /ways of working together



**Kidney Research UK**



## The law

### **Do nothing**

Deemed by law that you are willing to be an organ donor

### **Opt In**

Register your decision on the Organ Donor Register

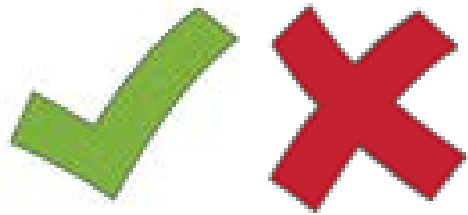


### **Opt out**

Register your decision on the Organ Donor Register

# What is the opt-out law?

Choice



Checks



Protected groups



Tests





**Make a decision**



**Share your decision**



**Register your decision**

# Getting more information



[www.organdonationscotland.org](http://www.organdonationscotland.org)

# Number of Opt-In and Opt-Out registrations in Scotland since 26th March 2021 by Ethnicity and Religion (Please note,

ethnicity and religion are stored separately to the main ODR and as such can include repeat registrations, removals and deaths.

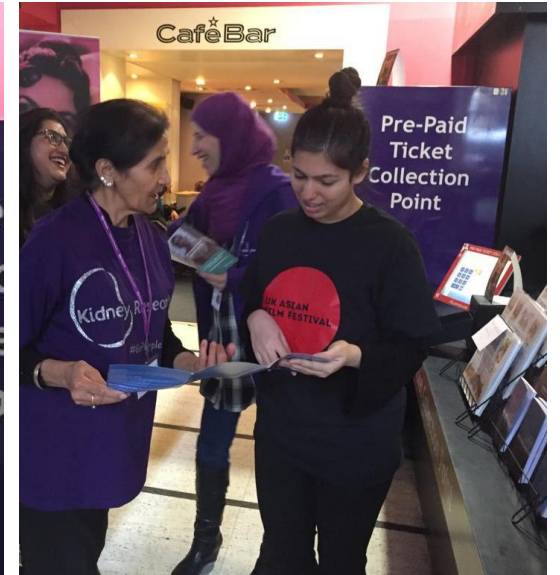
Ethnicity	OPTIN	OPTOUT	Total
01 White - British	7008	19042	26050
02 White - Irish	75	180	255
07 White - Other	554	1615	2169
11 Asian - Indian	76	163	239
12 Asian - Pakistani	34	1528	1562
13 Asian - Bangladeshi	4	52	56
17 Asian - Other	62	371	433
21 Black - Caribbean	3	23	26
22 Black - African	23	188	211
27 Black - Other	3	16	19
41 Mixed - White/Black African	13	22	35
42 Mixed - White/Black Caribbean	10	17	27
43 Mixed - White/Asian	38	62	100
47 Mixed - Other	38	88	126
60 Chinese	38	154	192
70 Other	29	310	339
99 Not reported	50839	6939	57778
Total	58847	30770	89617

Religion	OPTIN	OPTOUT	Total
Christian	2975	12625	15600
Hindu	33	43	76
Muslim	57	2183	2240
Jewish	8	54	62
Sikh	5	42	47
Buddhist	34	109	143
Other religion	98	591	689
No religion	4522	7325	11847
Not stated/not reported	51115	7798	58913
Total	58847	30770	89617





# Outreach work







Awards

All about having fun 😊



# Community PE projects - Wales

## New screening programme in Wales

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13 April 2023

Working in partnership with NHS Wales and Diabetes UK Cymru, and in consultation with Kidney Wales, we're spearheading a new project to screen for and prevent [chronic kidney disease \(CKD\)](#) in people with diabetes in Wales with existing kidney patients empowering at-risk patients.

### The problem

[Diabetes](#) is the leading cause of kidney failure in the UK – people with diabetes are four times more likely to need either kidney dialysis or a kidney transplant – and it is highly prevalent in South Asian and socio-economically deprived communities. When recognised early, kidney disease in people with diabetes can be effectively slowed down, thereby improving quality of life and delaying or preventing the transition to kidney failure.

# Community PE project - London

## Collaborating with high-risk communities to reduce kidney health inequalities

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26 August 2022

Among the African and Afro Caribbean community (AACC), kidney disease is known to be more common but also more often undiagnosed. With funding from Kidney Research UK, Roseline Agyekum and her team at King's College Hospital, are developing a peer educator led approach using urine testing technology and culturally appropriate educational materials to improve early detection of kidney disease in the AACC. This is being done in collaboration with Africa Advocacy Foundation (AAF), a Black owned media company Eagle London, and members of the AACC and they hope this will provide a model which can be translated to other high-risk communities.

There are around 1.2 million people with kidney disease in the UK who are undiagnosed. One possible reason is that awareness of [chronic kidney disease](#) (CKD) and engagement with healthcare is low within groups like the AACC, despite them being at high risk. Access to healthcare could also be a factor, impacting early diagnosis and intervention.

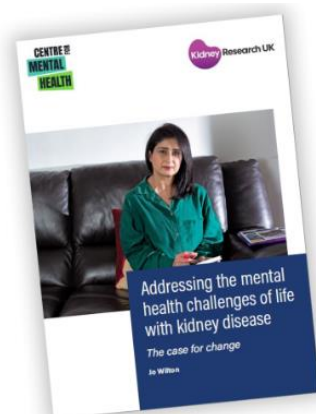


Roseline and her team want to better reach high risk groups like the AACC. The team plans to utilise a urine home-testing kit to help people with high blood pressure, identified by their GPs, to test their kidney function, where results show on a smartphone immediately. However, first they want to understand why there is low engagement about kidney disease within the AACC.

### Assessing the situation

# CKD Policy in Scotland

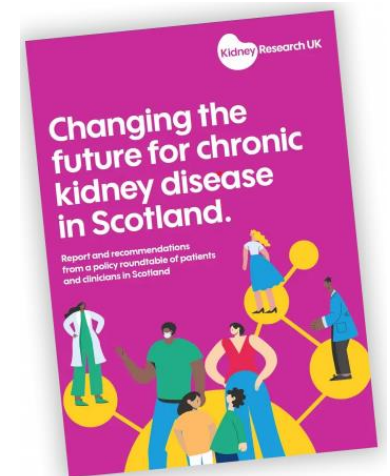
- Scottish CKD report – September 2022
  - Meetings with MSP- action plan for recommendations on prevention, early detection, clinical pathways for people diagnosed with CKD
  - [Changing the future for CKD in Scotland - Kidney Research UK](#)
- Mental Health Report (UK) – CKD report May 2023
- [Mental health impact on kidney disease patients revealed: our new report calls for urgent change to services - Kidney Research UK](#)



## Find out more

Read the full report in full; *Addressing the mental health challenges of life with kidney disease: The case for change.*

[Download the full PDF report](#)

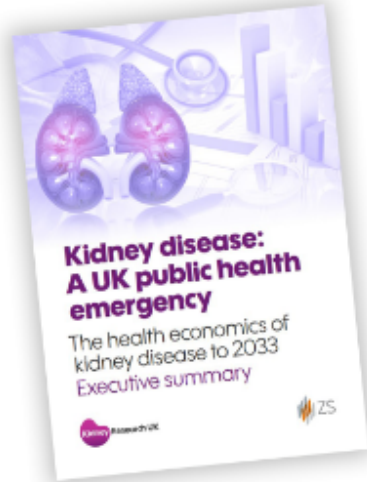


# Kidney disease is a public health emergency that threatens to overwhelm the NHS, major new report reveals

[Kidney disease is a public health emergency that threatens to overwhelm the NHS, major new report reveals - Kidney Research UK](#)

05 June 2023

**Kidney disease has become a public health emergency in the UK, with cases of the health condition growing so rapidly it risks costing the UK economy £13.9 billion annually by 2033 without significant government intervention, a major new report has found.**



Kidney Research UK has today published the independently produced report into the economic impact of kidney disease alongside stark projections that could see NHS capacity for dialysis treatment overwhelmed unless the disease becomes a government priority.

The report, [Kidney disease: A UK public health emergency](#), lays bare the growing costs of kidney disease, both in treating patients and in money lost to the economy by people being left unable to work due to time-consuming and gruelling treatment.

Written by health economics specialists, the report was created with insight and input from a group of 30 contributors including leading academics, clinicians from across the NHS and kidney patients.



# Fundraising

- Bridges Walk Glasgow – August 2023
- Tour o Borders – cycling
- Other activities
- Own activity
- Where does the money go ?



## Glasgow Bridges is back for 2023!

We're so excited to announce that our Bridges Walk is coming back to Scotland this summer!

Join us in Glasgow this August and together we will build bridges to transform treatments. Walk, dash and reel your way to help change the lives of the 850 million people living with kidney disease worldwide.

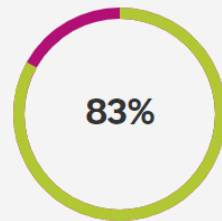
We're with you every step of the way for what will be a brow day!

Festival Park, Glasgow 20 August 2023 Registration fee £5

Distance: long route max 7 miles / short route approx 1 mile

Aim to raise £150

## How your fundraising supports vital research



Of all the money we raise, we invest 83p out of every pound directly into our research and awareness work, with 17p helping to raise the next pound to sustain our work into the future.



Tale of kidney transported 400 miles from Glasgow to London for transplant

10 February 2023

[Read More](#)



'I'm running the London Marathon to say thanks for my brother's transplant'

9 January 2023

[Read More](#)



Nearly 100 Lancashire tractors to run for Kidney Research UK

22 December 2022

[Read More](#)



Family's tribute fund for mum's chosen charity

25 November 2022

[Read More](#)

# Keep in touch

## Have you recently been diagnosed with kidney disease?

Request your free Kidney Kit today. You'll find tips and support from kidney patients, delicious recipes, simple exercise plans and more.

Get your free Kidney Kit





# kidney disease ends here.

Online - [www.kidneyresearchuk.org](http://www.kidneyresearchuk.org)

Twitter: [@Kidney\\_Research](https://twitter.com/Kidney_Research), F/B,

TikTok

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T: 0300 303 1100 | E: [name@kidneyresearchuk.co.uk](mailto:name@kidneyresearchuk.co.uk) | [www.kidneyresearchuk.org](http://www.kidneyresearchuk.org)