

Living Donation Scotland



“The feeling that I had not been expecting was the sense of wellbeing after I donated, knowing I had transformed another person's life and their future.”

John, Kidney Donor

For Information on
Living Kidney Donation visit:
livingdonationscotland.org

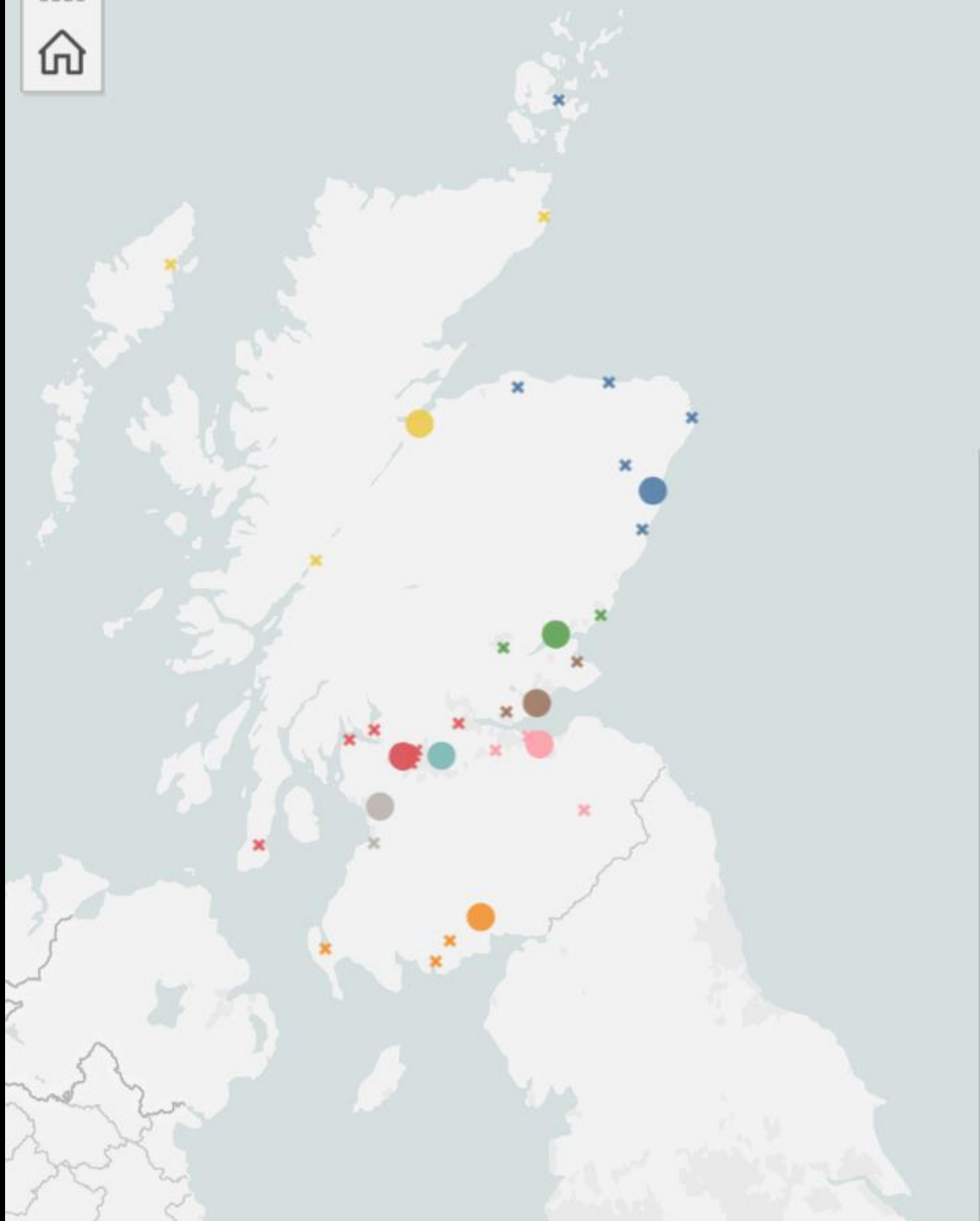


www.livingdonationscotland.org

livingdonationscotland@nhs.net

@livingdonorscot

Colin Geddes/Julie Glen/Jen Lumsdaine





ALPHA

This is a new site, your [feedback](#) will help us to improve it.

[Home](#) > [Specialist healthcare](#) > [Specialist services](#)

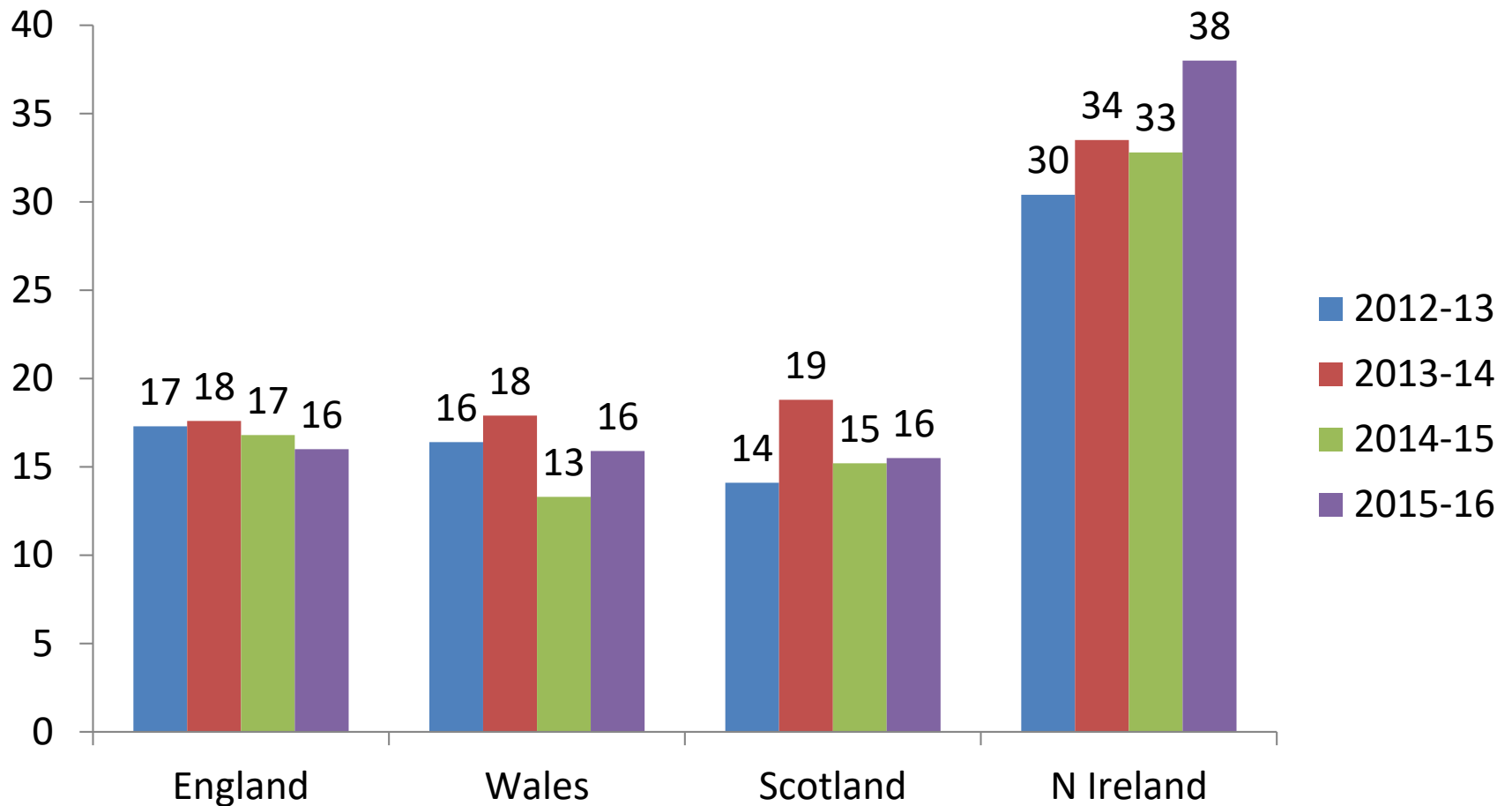
Renal transplantation: adult

Published on 13 December 2019

The Adult Renal Transplantation Service is for people over the age of 16 living with end-stage kidney failure.

This national service is jointly based at units in the Royal Infirmary of Edinburgh and the Queen Elizabeth University Hospital in Glasgow.

Living donors pmp by UK country



Jen Lumsdaine



Living Donation Scotland Project Board

Scottish Government

Commissioning Programme Manager
Programme Manager, Donation & Transplantation
Programme Support Officer

Hospital management

Clinical Service Manager, Edinburgh
Clinical Service Manager, Glasgow

Patient

Recipient rep, Glasgow
Donor rep, Edinburgh

Clinical

Consultant Paediatric Nephrologist, Glasgow
Transplant Coordinator, Glasgow
Transplant Coordinator, Edinburgh
Consultant Nephrologist, Aberdeen
Consultant Nephrologist, Edinburgh
Consultant Nephrologist, Glasgow
Consultant Transplant Surgeon, Glasgow
Consultant Transplant Surgeon, Edinburgh



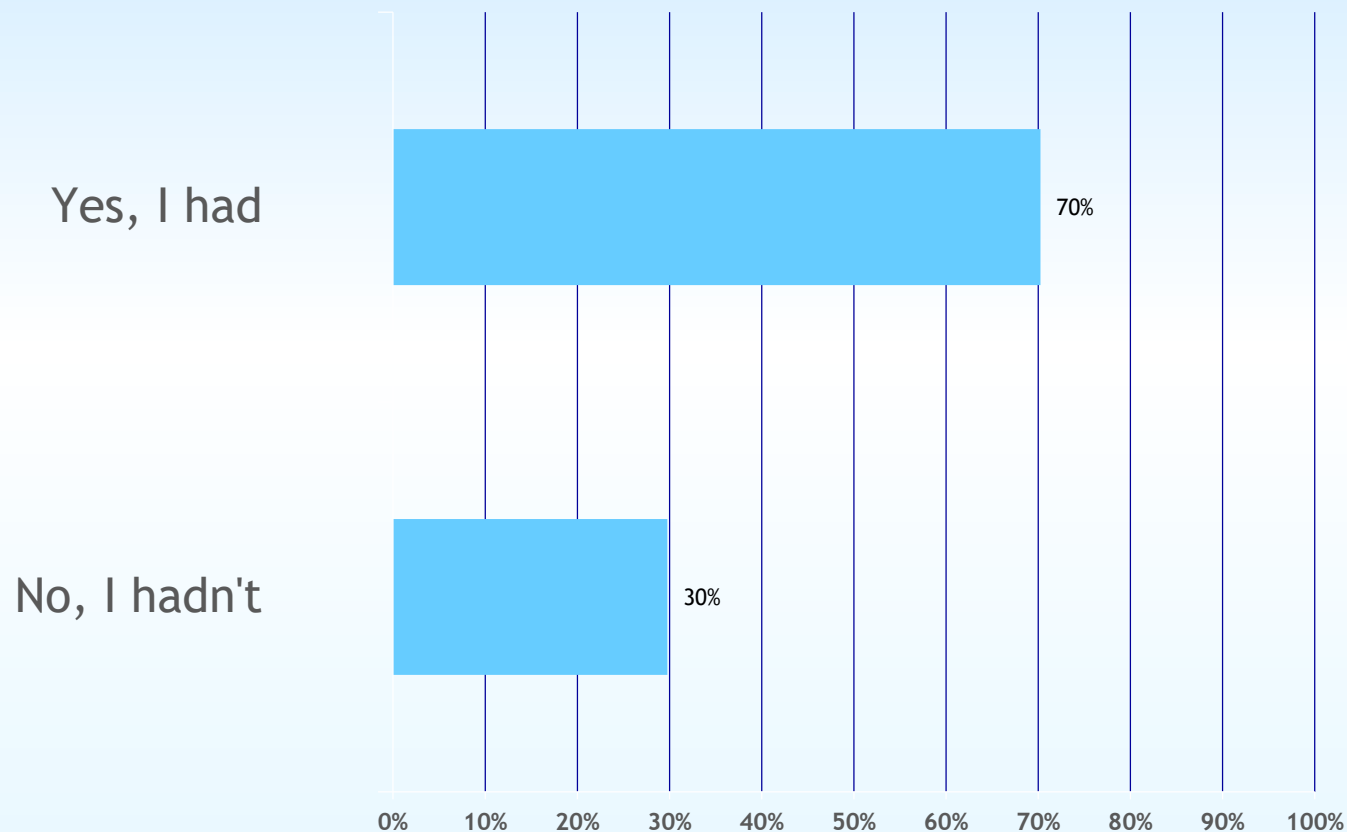
Project Board Aim

- Ensure equity of access to living donor transplant in Scotland
- Timely transplantation
- Appropriate information
- Increase public awareness

Living Kidney Donation

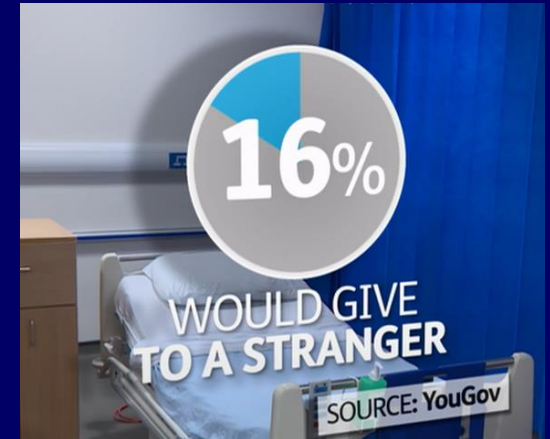
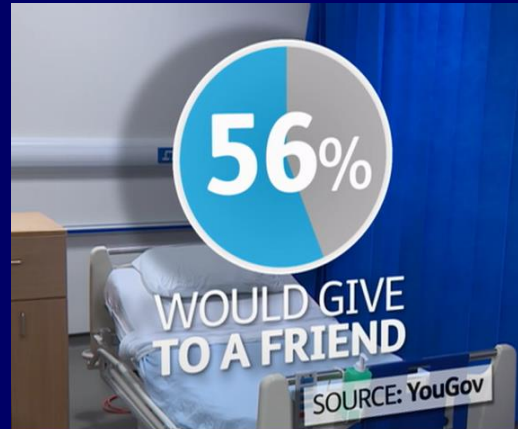
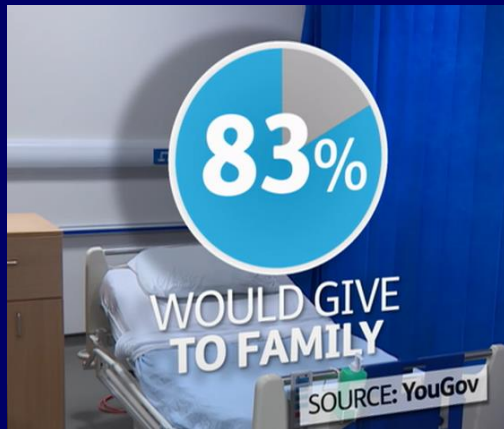
YouGov Survey March 2019

YCL_q2. "Living kidney donation" refers to a living person donating one of their kidneys for use in organ transplantation. The person then continues to live with one kidney. Before taking this survey, had you heard of 'living kidney donation'?



Unweighted base: All Scottish adults (1000)

YouGov Survey 2019



Website

- Accurate information
- Contact details for each unit
- Post code finder
- Interactive case studies
- Info for health care professionals
- Easy to navigate
- Link to LivingDonationScotland email for enquiries

[Home](#) > [Tell me about Living Donation](#) > [Get in touch](#) > Welcome to Aberdeen Royal Infirmary Renal Unit.



Welcome to Aberdeen Royal Infirmary Renal Unit.

We believe that living donor transplantation is the best option for our patients who are waiting on a kidney transplant, and welcome enquiries from potential donors, whether a family member or friend, or any potential altruistic (volunteer) donors.

Contact the team

Our team of Specialist Transplant Nurses and Nephrologists will take you through the process. We arrange most of your tests here in Aberdeen, including a review by one of the Transplant Surgeons from Edinburgh. When all your tests are satisfactory we refer you to the transplant unit in Edinburgh for your final tests.

[More about living donation](#)

[The process](#)

[Meet the transplant teams](#)

[Donor stories](#)

[Get in touch](#)

Initial Meeting – Nephrologists / LC nurses

- Nephrologists / LC nurses were identified as key to implement change
- 'Tx first' and bust myths!!
- Identified gaps in knowledge
- LD Info packs evolved!!



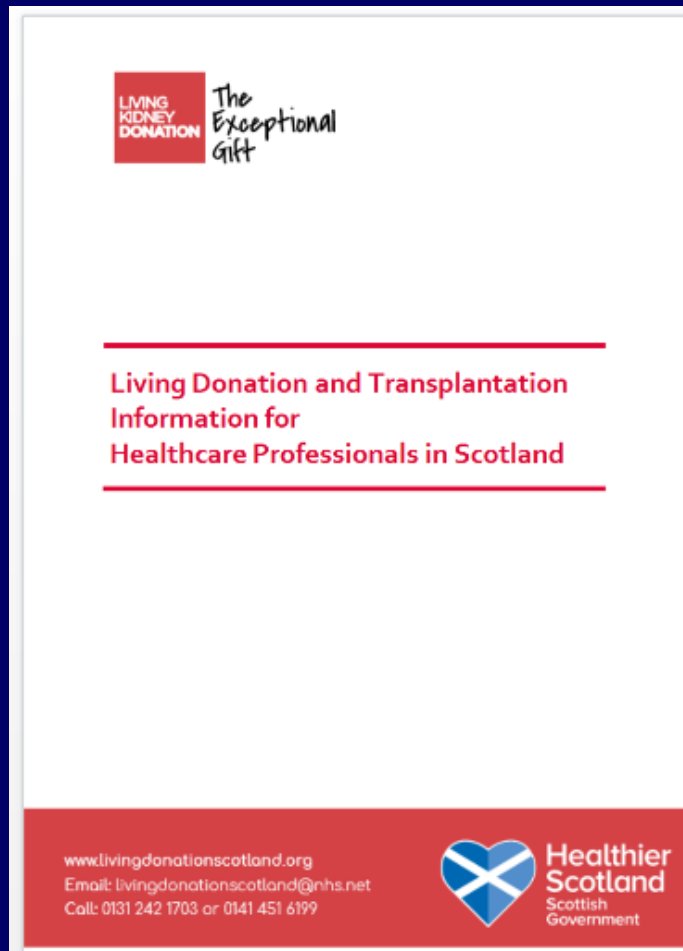
Living donor information pack



Annual Meeting

- Well attended
- Share good practice / successes / goals / concerns / etc
- HP booklet evolved!!

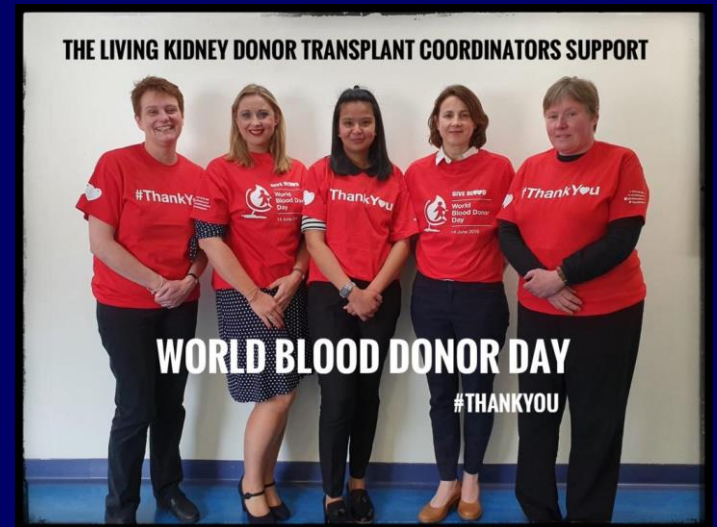
Healthcare professionals



- Primary Care teams
- Link nephrologists and link nurses
- SRA
- Overcoming 'pre-dialysis' thinking

Blood Transfusion Centres

- Leaflets/pull up banners in donor centres
- Social media sharing



Coordinated Publicity

- Across all media
- Across all healthboards
- Targeted times of the year

Living donation awareness week March 2019 (World Kidney Day)

TRANSPLANTS

The phone call Rachel will never forget

By CAROLINE WILSON

When Rachel Wilson was 18, she was diagnosed with kidney failure. She had to start dialysis, but she didn't want to. She wanted to live. So she decided to donate a kidney to a stranger. It was a life-changing decision, but it was worth it. She now lives a healthy life, and her kidney is still working perfectly.

Sisters' joy at kidney success

By CAROLINE WILSON

Two sisters, Rachel and Sarah, have both donated kidneys to strangers. They are now living healthy lives, and their kidneys are still working perfectly. They are proud of their decision and the success of their donation.

Donor: Giving away kidney is the best thing I ever did

By DOUGLAS BARNIE

John Giesche, 72, was a consultant transplant surgeon at Edinburgh Royal Infirmary. He donated his kidney to a stranger, and he says it was the best thing he ever did. He now lives a healthy life, and his kidney is still working perfectly.

Donated kidney a 'wonderful gift'

By DOUGLAS BARNIE

John Giesche, 72, was a consultant transplant surgeon at Edinburgh Royal Infirmary. He donated his kidney to a stranger, and he says it was the best thing he ever did. He now lives a healthy life, and his kidney is still working perfectly.

Selfless Jennie (26) donates a kidney to save stranger's life

By CAROLINE WILSON

Jennie, 26, from Bellshill, in Lanarkshire, was rushed to hospital a week after she had a kidney transplant. She had donated her kidney to a stranger, and she says it was the best thing she ever did. She now lives a healthy life, and her kidney is still working perfectly.

Caring kidney donor meets new dad she gave a future

By CAROLINE WILSON

The transplant was carried out on January 22 at the Queen Elizabeth University Hospital, with the pair meeting for the first time as James was discharged after surgery. Alan said: "When Jennie came in to see me, I must have said thanks about a hundred times. It was a total relief to see her, and to know that she was safe. I was a bit nervous, but she was so kind and caring. She was a wonderful gift to me, and I will always be grateful to her."

BBC NEWS

Marked increase in kidney transplants

An increase is reported in living donors and those agreeing to donate organs can be used after their death.

9 hours ago Scotland



BBC NEWS

'It was part of a kidney swap chain'

Mandy Murray's husband Graham gave his kidney to someone in Belfast so his wife got a transplant in return.

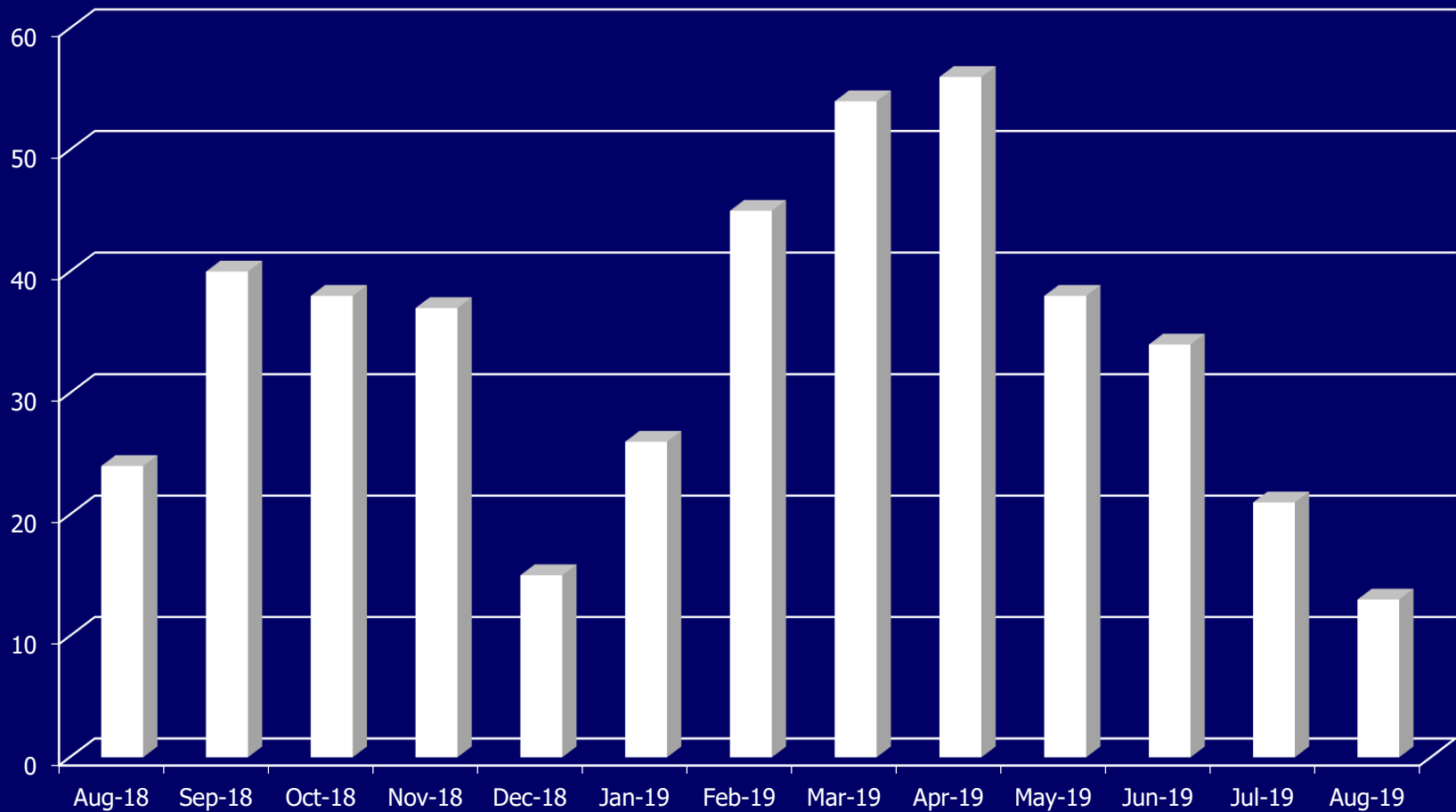
9 hours ago Scotland

Organ Donation Scotland – Living Donation

- **Website (livingdonationscotland.org)**
- Comparison between 11 - 15 February 2019 and 11 - 15 March 2019:
- **187 page views between 11 – 15 Feb and 2,603 page views between 11-15 March.**
- For that week in February, living kidney pages accounted for **8% of traffic to the Organ Donation Scotland website**
- In March it was **44% of the traffic**

- • During 11 - 15 March, **86% of the traffic to the pages were from new visitors and on average they spent around 3 minutes on the site.**
- **Response**
- Living Donor Teams in Scotland received **over 100 living donation enquiries**
- **66 altruistic** and 41 directed = 107 total

Registration forms returned



Living donor information events



4.15pm
The Surgery and Recovery
Mr John Terrace, Consultant Transplant Surgeon, Edinburgh

4.30pm
After the operation
Dr Paul Phelan, Consultant Nephrologist, Edinburgh

4.45pm
Donor and Recipient Stories
Cearda & Les McGregor
Julie Robertson & Anna Day
Alexander Barelle

5.00pm
Questions and Close

LIVING KIDNEY DONATION The Exceptional Gift

Home-based family intervention increases knowledge, communication and living donation rates: a randomized controlled trial.

Ismail SY¹, Luchtenburg AE, Timman R, Zuidema WC, Boonstra C, Weimar W, Busschbach JJ, Massey EK.

Author information

Abstract

Our aim was to develop and test an educational program to support well-informed decision making among patients and their social network regarding living donor kidney transplantation (LDKT). One hundred sixty-three patients who were unable to find a living donor were randomized to standard care or standard care plus home-based education. In the education condition, patients and members of their social network participated in home-based educational meetings and discussed renal replacement therapy options. Patients and invitees completed pre-post self-report questionnaires measuring knowledge, risk perception, communication, self-efficacy and subjective norm. LDKT activities were observed for 6 months postintervention. Patients in the experimental group showed significantly more improvements in knowledge ($p < 0.001$) and communication ($p = 0.012$) compared with the control group. The invitees showed pre-post increases in knowledge ($p < 0.001$), attitude toward discussing renal replacement therapies ($p = 0.020$), attitude toward donating a kidney ($p = 0.023$) and willingness to donate a kidney ($p = 0.039$) and a decrease in risk perception ($p = 0.003$). Finally, there were significantly more inquiries (29/39 vs. 13/41, $p < 0.001$), evaluations (25/39 vs. 7/41, $p < 0.001$) and actual LDKTs (17/39 vs. 4/41, $p = 0.003$) in the experimental group compared with the control group. Home-based family education supports well-informed decision making and promotes access to LDKT.

REACH project

ORGAN
DONATION
SCOTLAND

Call us for more information on **0300 123 2323**

[Register your choice](#)

[What is organ donation?](#)

[How to register your choice](#)

[Tell your family & friends](#)

[Living Donation](#)

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Search



[Home](#) > Renal Education and Choices @ Home (REACH) Project

Renal Education and Choices @ Home (REACH) Project

**Renal
Education
And
Choices @
Home**



We know that patients can find it difficult to talk openly about their kidney disease, and that raising the subject of live donor kidney transplantation (LDKT) can seem like an insurmountable hurdle. We know too that patients and their loved ones can have misconceptions about LDKT. These realities combine to reduce the likelihood of accessing pre-emptive LDKT as a preferred treatment option for many patients.

News Archive

[November 2019](#)

[June 2019](#)

[2019](#)

[2018](#)

[2017](#)

[2016](#)

[2015](#)

[2014](#)

[2013](#)

[2012](#)

Kidney Charities Event

- Engage with frontline workers and volunteers
- New legislation on opt out
- Key facts
- Highlight the benefit of Living Donation

Young potential donors (<25 yrs)

- National guideline for psychological assessment produced 2018.

**In 2019 we agreed we
were no longer a
'Project'!!!**

Welcome to....

The Scottish Board for
Living Donation

Aim

- **“Any individual in Scotland who would benefit from kidney transplantation has timely access with no or minimal time on dialysis”**

HUGE thank you to:

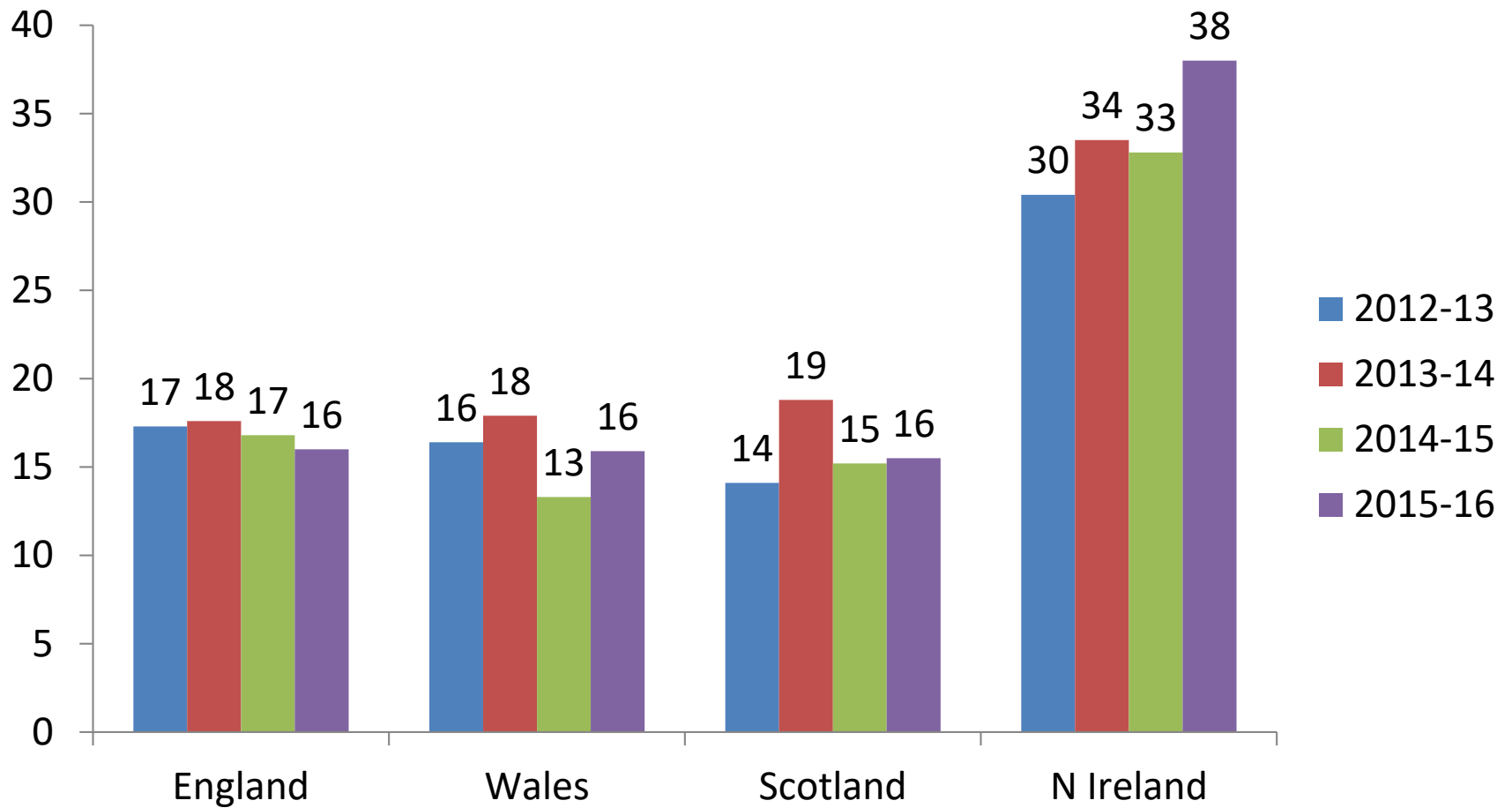
- Jen Lumsdaine
- The Scottish Government
- The Scottish Project Board for LKD



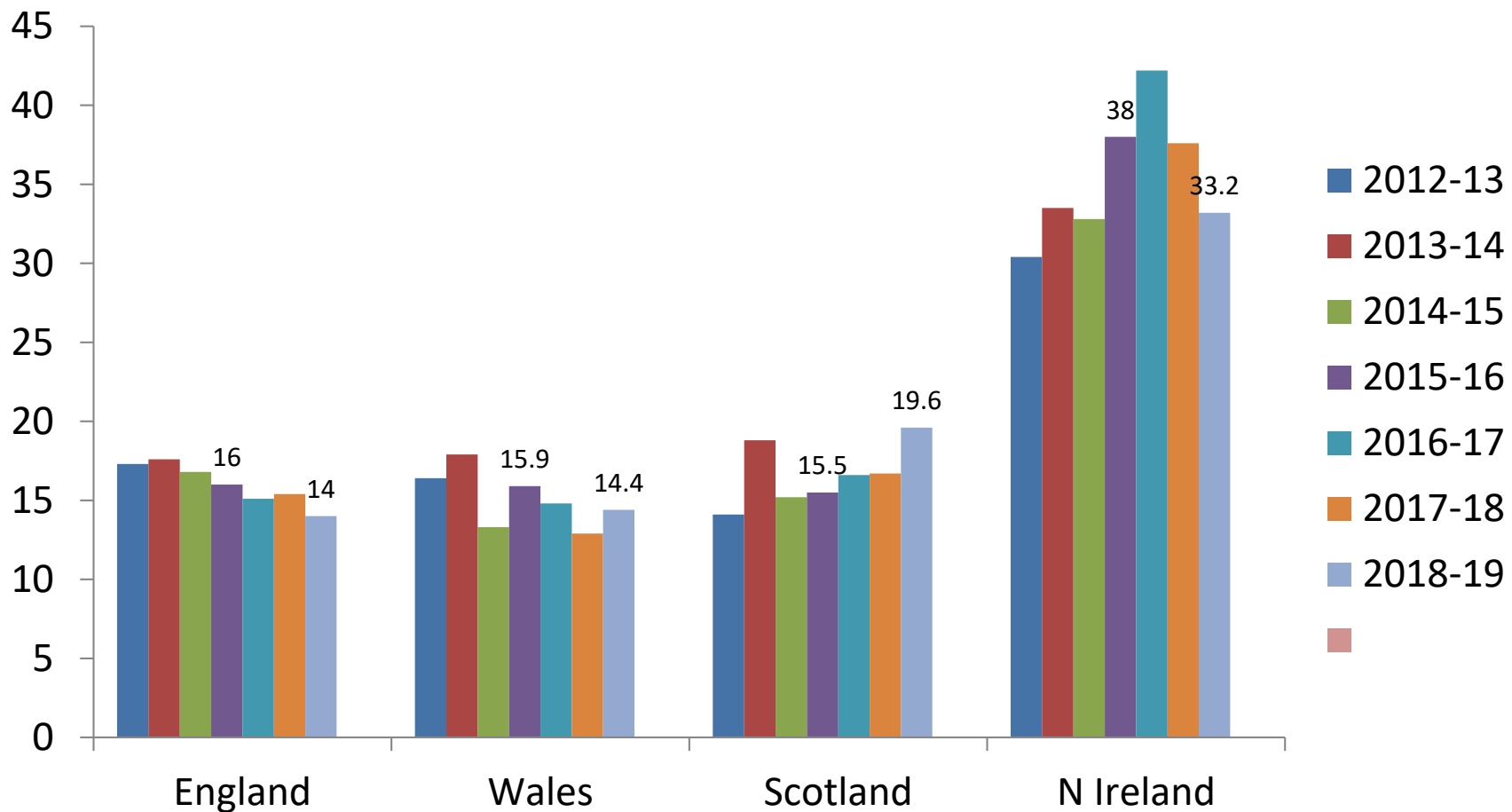
Results?



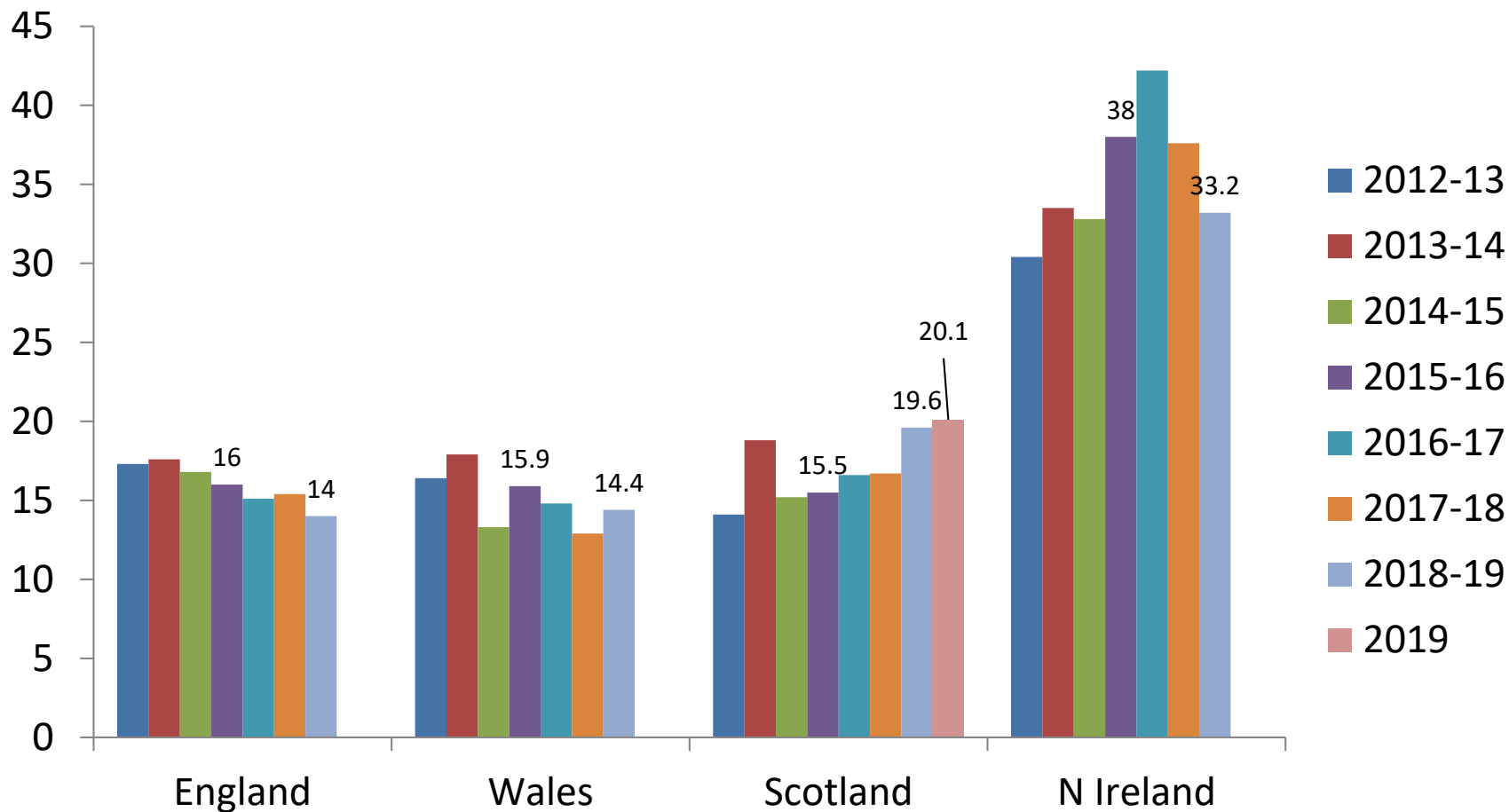
Living donors pmp by UK country



Living donors pmp by UK country



Living donors pmp by UK country



Living donor transplant Scotland 2019

	East	West	Scotland
Living donors	55	54	109
Living donor transplants (adult)	48	46	94
Altruistic	11	4	15
NKSS	10 (18%)	17 (31%)	27 (25%)

Challenges



Challenges

- Not reached target of 26pmp

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- Transplant first message

Challenges

- Not reached target of 26pmp
- Transplant first message
- BAME/deprivation

Interaction between socioeconomic deprivation and likelihood of pre-emptive transplantation: influence of competing risks and referral characteristics - a retrospective study.

Gillis KA¹, Lees JS¹, Ralston MR², Glen JA², Stevenson KS², McManus SK², Geddes CC², Clancy M², Traynor JP², Mark PB¹.

Author information

Abstract

Socioeconomic deprivation (SED) influences likelihood of pre-emptive kidney transplantation (PET), but the mechanisms behind this are unclear. We explored the relationships between SED and patient characteristics at referral, which might explain this discrepancy. A retrospective cohort study was performed. SED was measured by Scottish Index of Multiple Deprivation (SIMD). Logistic regression evaluated predictors of PET. A competing risks survival analysis evaluated the interaction between SED and progression to end-stage kidney disease (ESKD) and death. Of 7765 patients with follow-up of 5.69 ± 6.52 years, 1298 developed ESKD requiring RRT; 113 received PET, 64 of which were from live donors. Patients receiving PET were "less deprived" with higher SIMD (5 ± 7 vs. 4 ± 5 ; $P = 0.003$). This appeared independent of overall comorbidity burden. SED was associated with a higher risk of death but not ESKD. Higher SIMD decile was associated with a higher likelihood of PET (OR 1.14, 95% CI 1.06, 1.23); the presence of diabetes and malignancy also reduced PET. SED was associated with reduced likelihood of PET after adjustment for baseline comorbidity, and this was not explained by risk of death or faster progression to ESKD. Education and outreach into transplantation should be augmented in areas with higher deprivation.

Challenges

- Not reached target of 26pmp
- Transplant first message
- BAME/deprivation
- Psychology resource

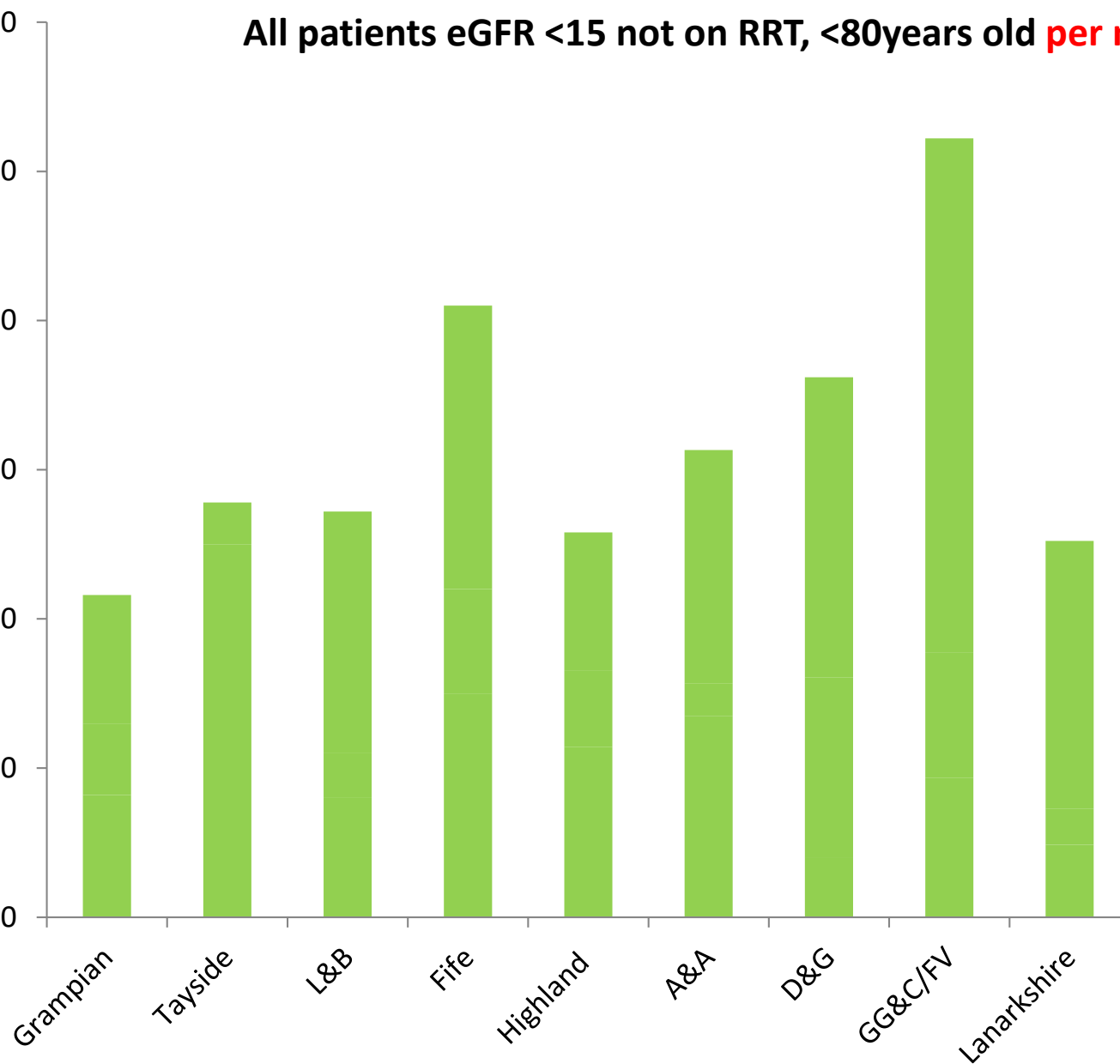
Challenges

- Not reached target of 26pmp
- Transplant first message
- BAME/deprivation
- Psychology resource
- Data collection/granularity (eg recording 'no live donor' has potential negatives')
- Data interpretation

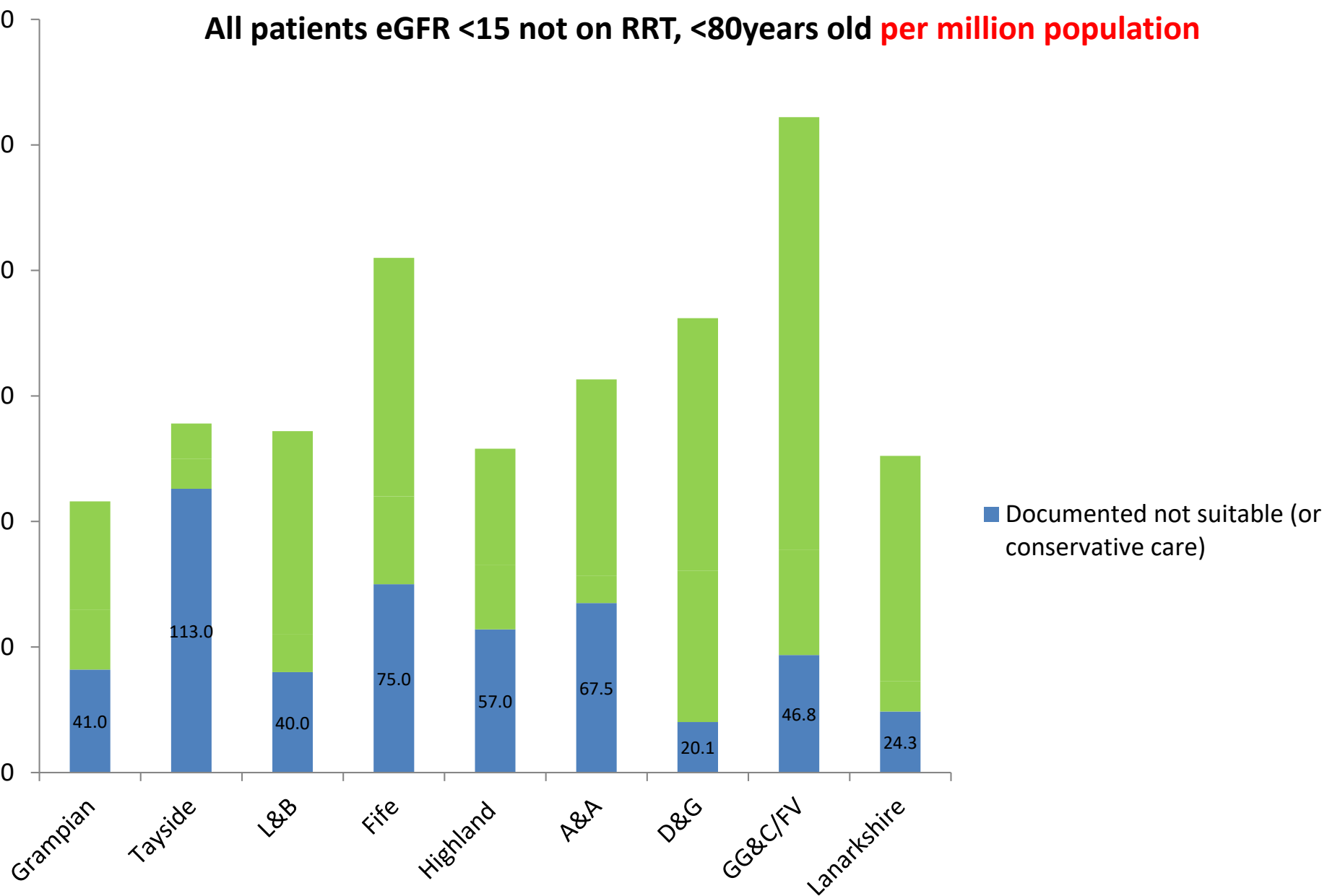
Challenges

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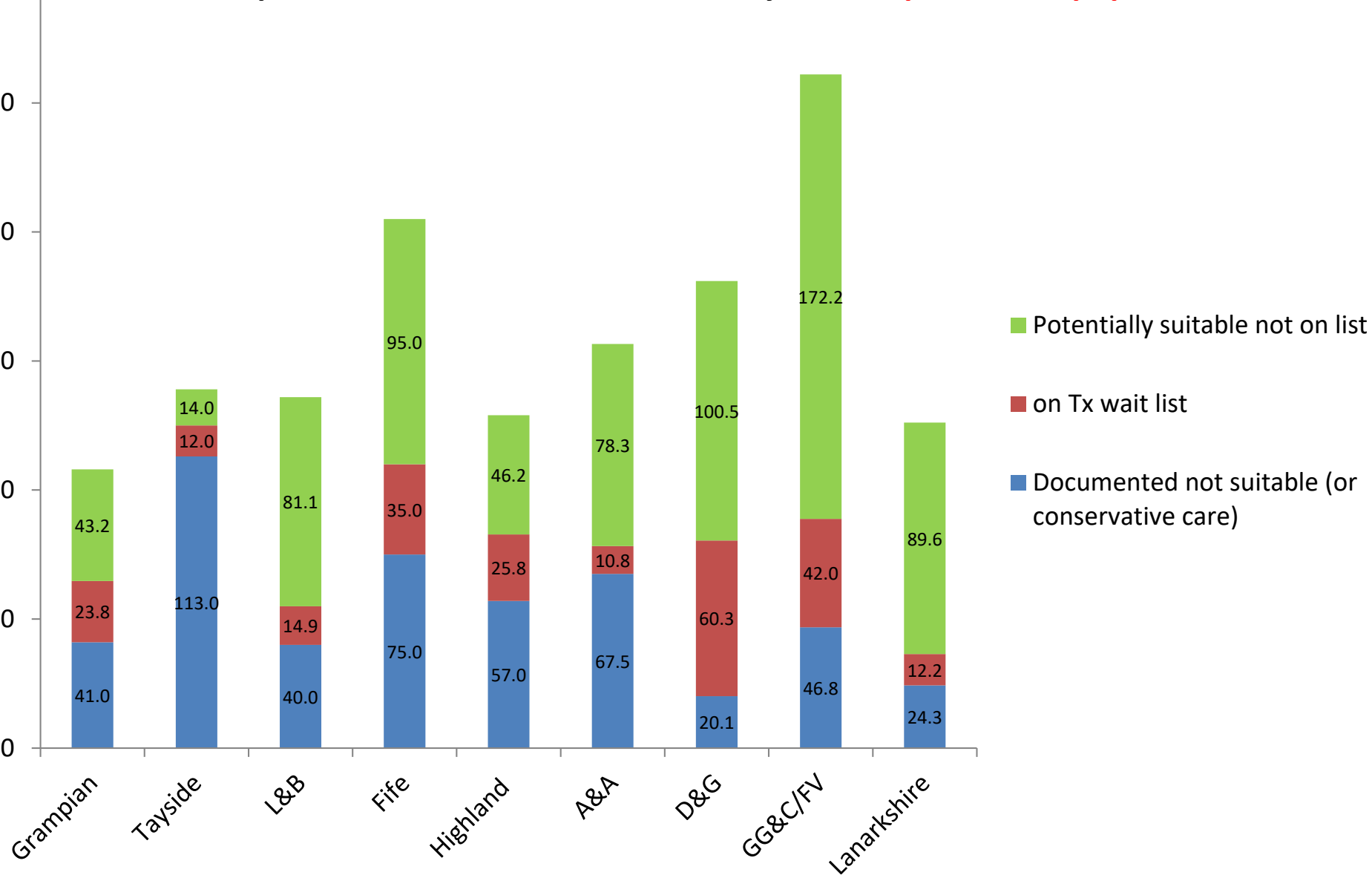
All patients eGFR <15 not on RRT, <80years old per million population



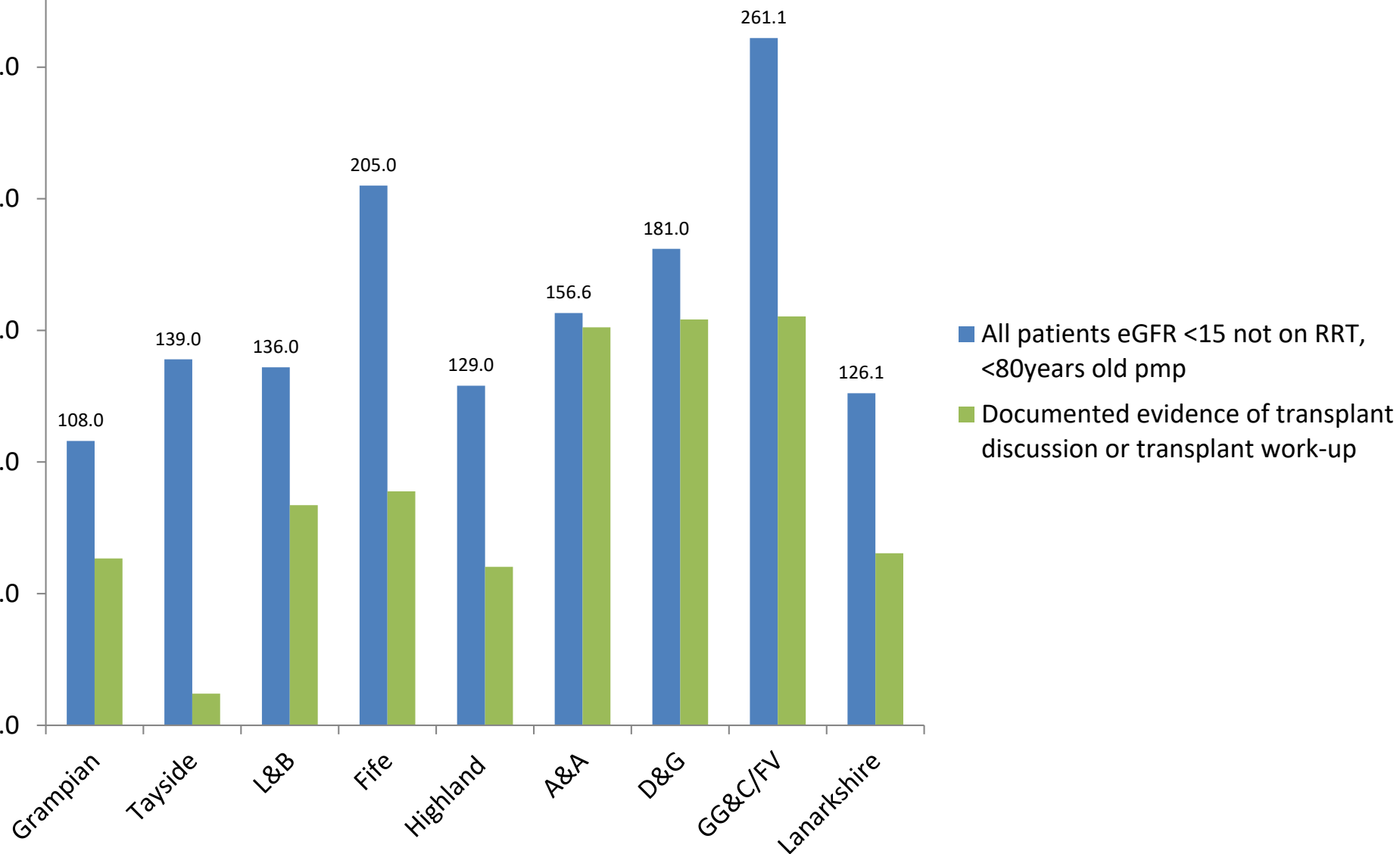
All patients eGFR <15 not on RRT, <80years old per million population



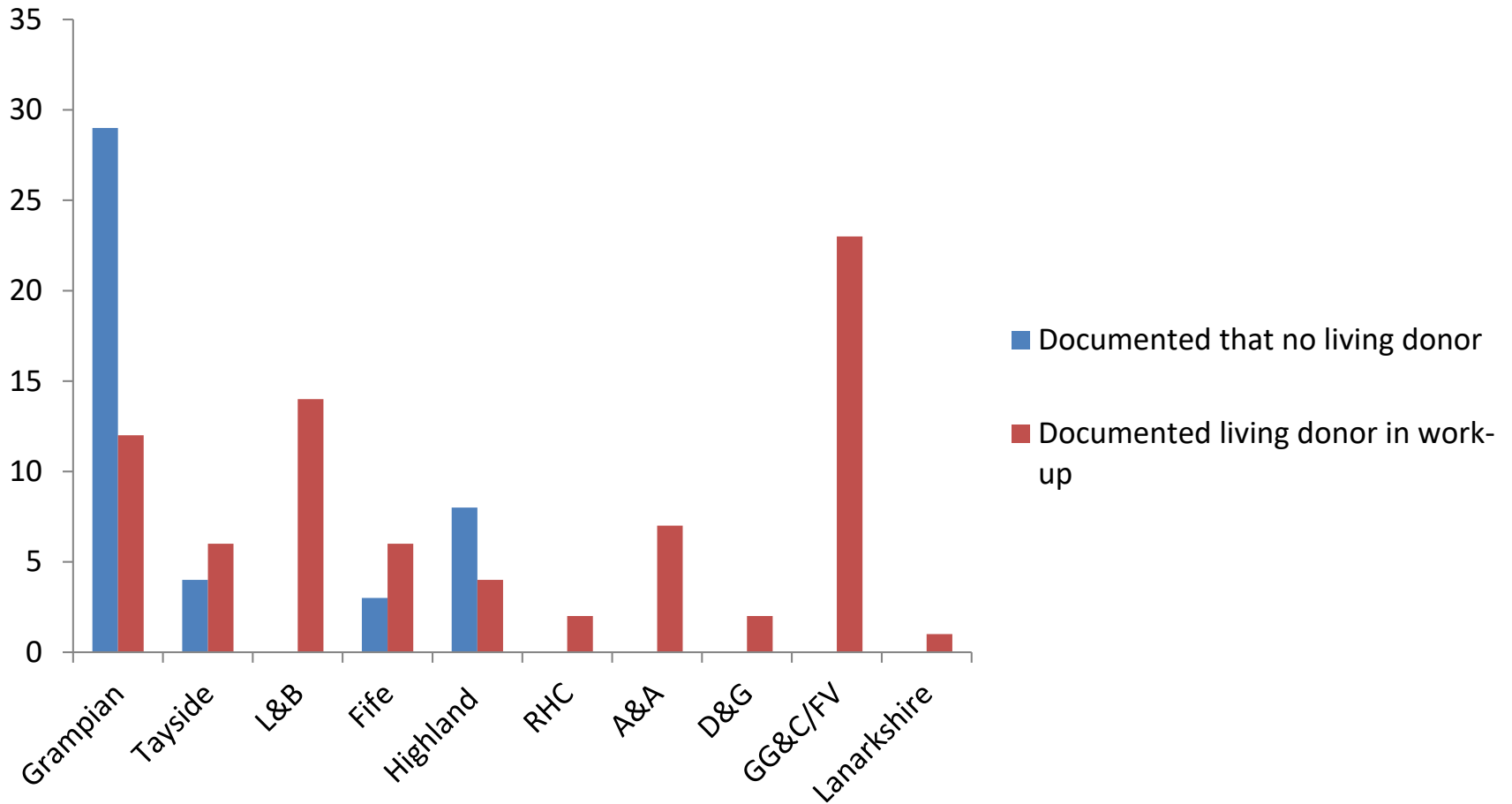
All patients eGFR <15 not on RRT, <80years old per million population



eGFR <15 not on RRT, <80years old **per million population**



Actual number documented living donor/no living donor in work up



Challenges

- Not reached target of 26pmp
- Transplant first message
- BAME/deprivation
- Psychology resource
- Data collection/granularity (eg recording 'no live donor' has potential negatives')
- Data interpretation

Future



Future

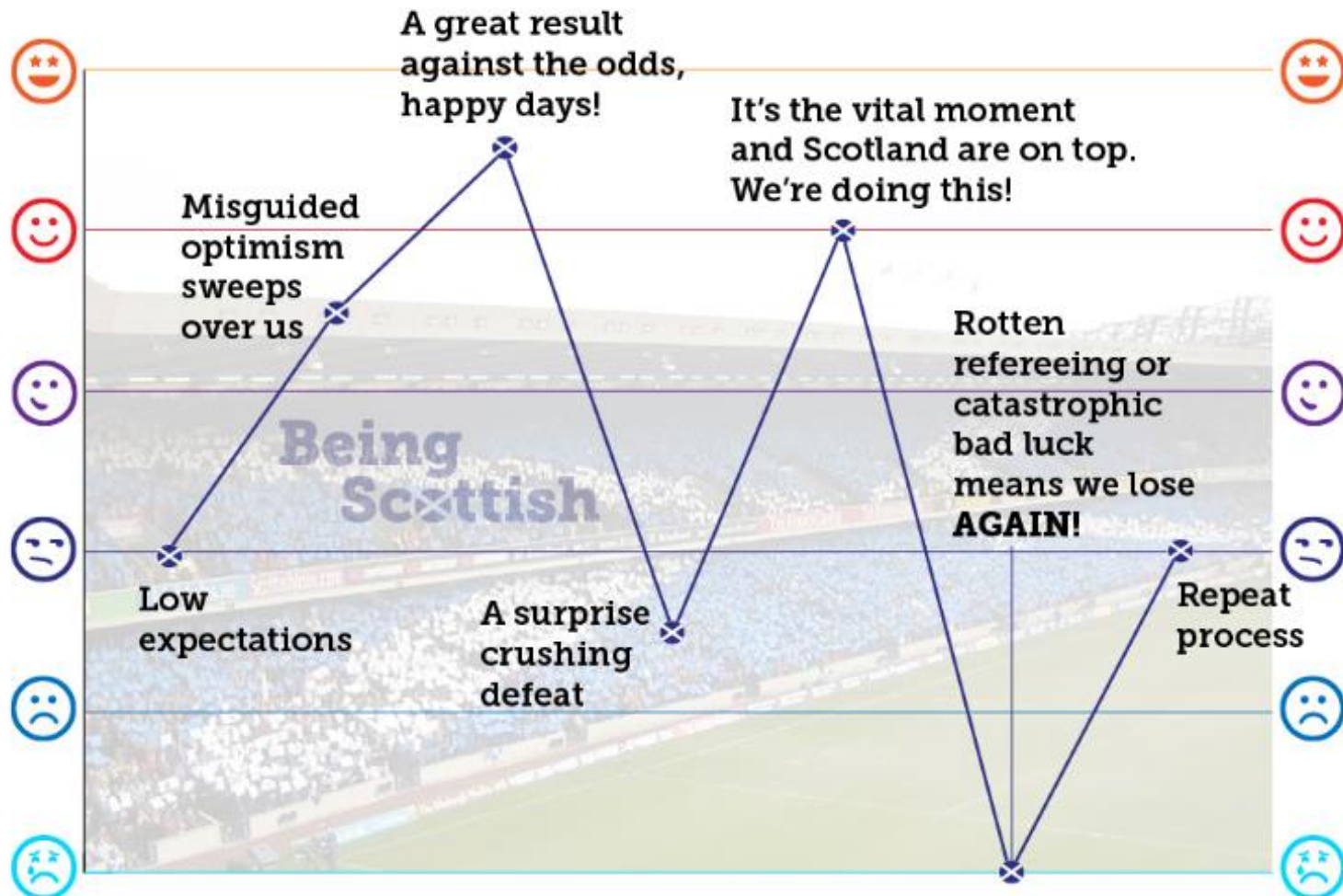
- Targeting resource to identify potential living donors
- Can we replicate REACH program across Scotland?
- Have we realised potential of social media?
- Impact of 'opt-out' legislation

Anybody wants
to say anything?

I'm vegan

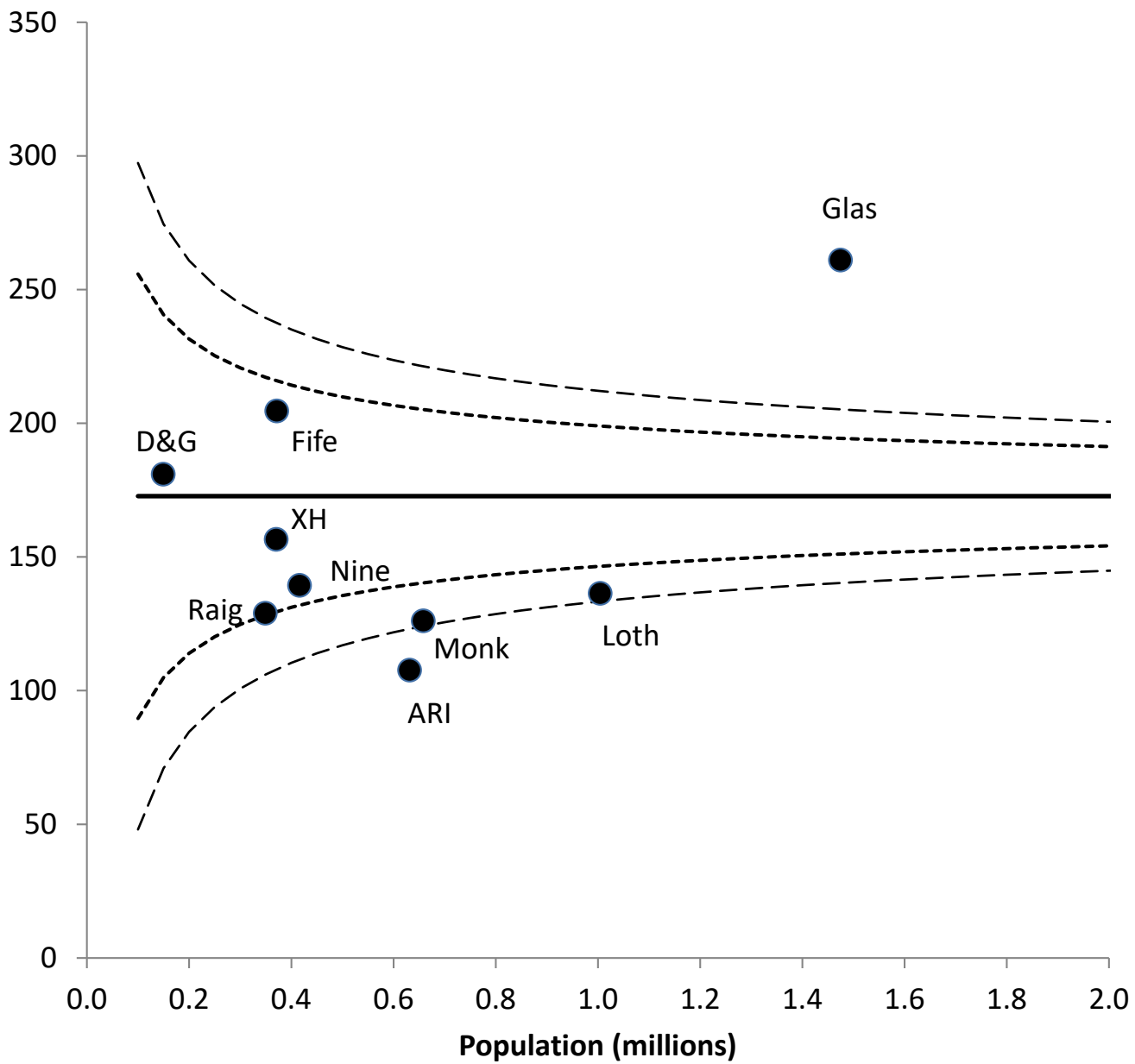


Guide to Supporting Scotland

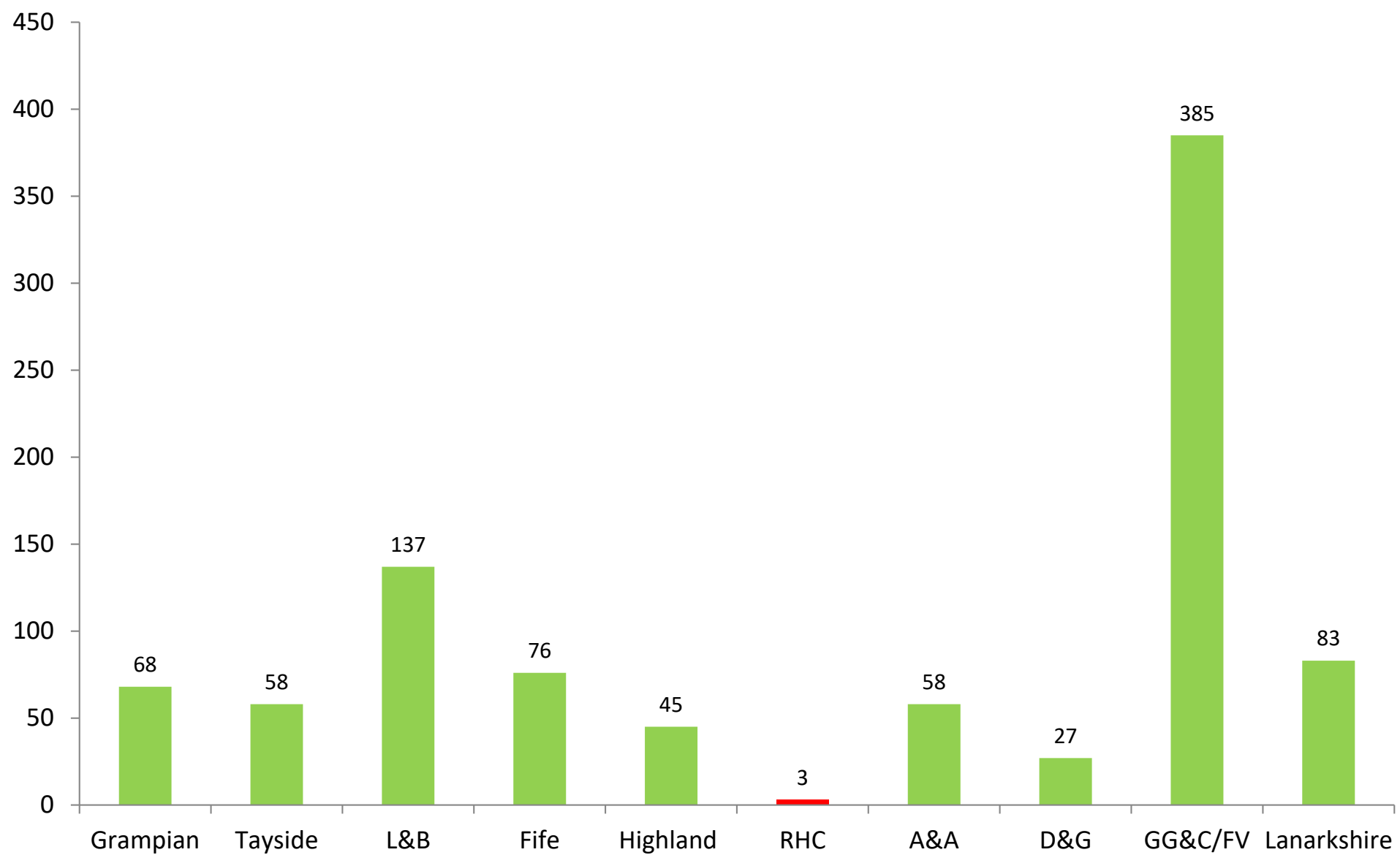


- Total Live Donor Transplants 48 +46
-
- Total Live Donor Nephrectomies 55 +54
- Exports: 12 +11
- Altruistic Donors to elsewhere 11 +4
- Nephrectomy for other centre 1 +2 +5 nephrectomies for RHC
-
- Imports: 5
- Altruistic donors: 3 +3
- End of chain donors: 1
- Direct Import from other centre: 1
-
- National Kidney Sharing Scheme
- 10 live transplants in 2019 +17
-
- 3 altruistic donors to Edinburgh patients
- 1 end of chain donor
- 6 donor/recipient pairs
-

Patients aged <80
attending with
eGFR <15mL/min



All patients eGFR <15 not on RRT, <80years old



eGFR <15 not on RRT, <80years old **per million population**

