

THE RENAL
ASSOCIATION
founded 1950



UK RENAL REGISTRY

SUMMARY OF ANNUAL REPORT

Analyses of paediatric data to the end of 2018



INTRODUCTION

I am very excited to introduce the first summary focusing on kidney data of children under 16 and 16-18 years old. A big thank you to the Renal Registry for collecting and summarising the data from all 13 paediatric kidney centres in the UK. The report reflects data from the period prior to the coronavirus pandemic and provides an invaluable insight into the numbers of children affected with kidney disease, their treatment and outcome.



Kamal Dhesi
Member of the
Renal Association Patient Council

Kidney failure is a cruel disease. It affects many individual milestones, growth and weight, and everyday choices: from what we can eat and drink, to managing medication and appointments. This is done while still trying to create as many normal experiences for our children, participating in family events, hobbies and even school trips and holidays. But these things are possible to achieve with support. The report highlights that the total number of children in the UK with kidney failure has increased, reflecting that many children are living longer with the treatment they are receiving. These children then transfer to adult services, most with a functioning kidney transplant. As a mother of a child who started dialysis at the age of 6 months, I know how far science has come.

I hope you, like myself, find the data in this report informative. As parents of kidney patients, we start this journey with no or little information, therefore any reliable and up to date data is empowering. It allows us to have discussions with professionals to ensure the right choices for our children.

We are living through unprecedented times, where our routines and our choices have been greatly affected: from having to protect and shield the vulnerable, to delays in transplants. These experiences will help us to start a discussion about the future choices of our children, in partnership with different professionals involved, including schools and social care. We need to ensure an approach that is flexible but also holistic.

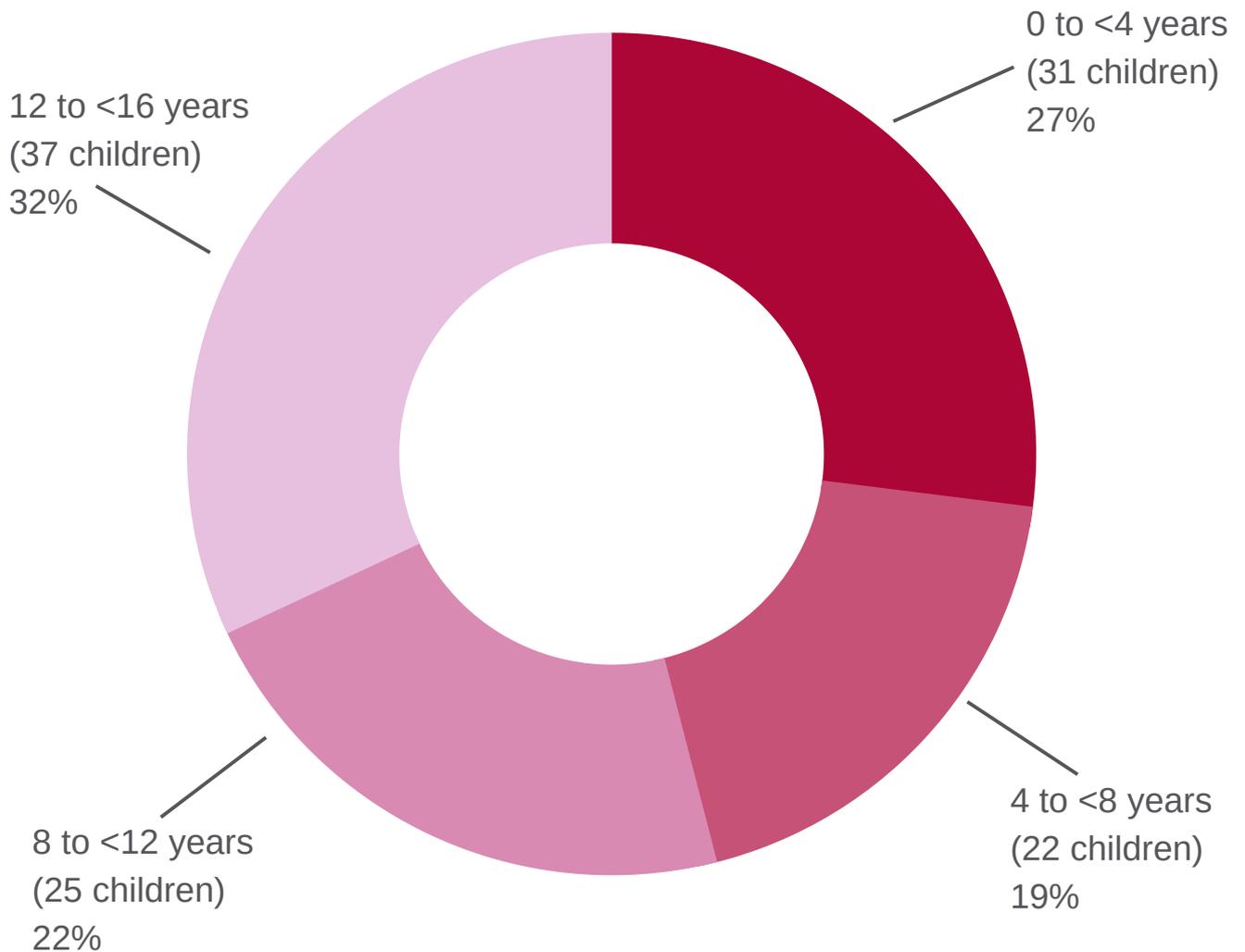
If you would like to give feedback on this report or get involved with the Renal Association, please do get in touch. Only by getting involved will we make our voices heard and make a difference for all those affected by kidney disease.

CHILDREN STARTING TREATMENT

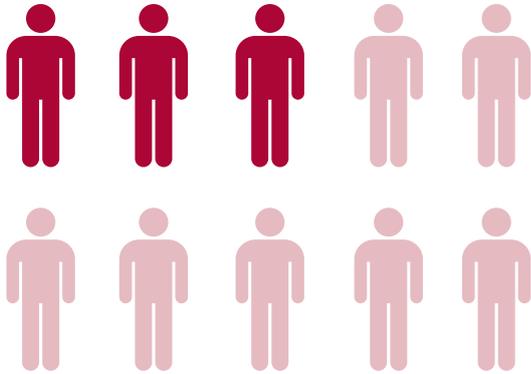
In 2018, 115 children under 16 years of age started long-term treatment for kidney failure, which equated to 9 children in every million of the UK child population. This was a similar number of children compared with previous years. Approximately two-thirds were male.



Most children who started long-term treatment were aged 12-16 years.



CHILDREN STARTING TREATMENT

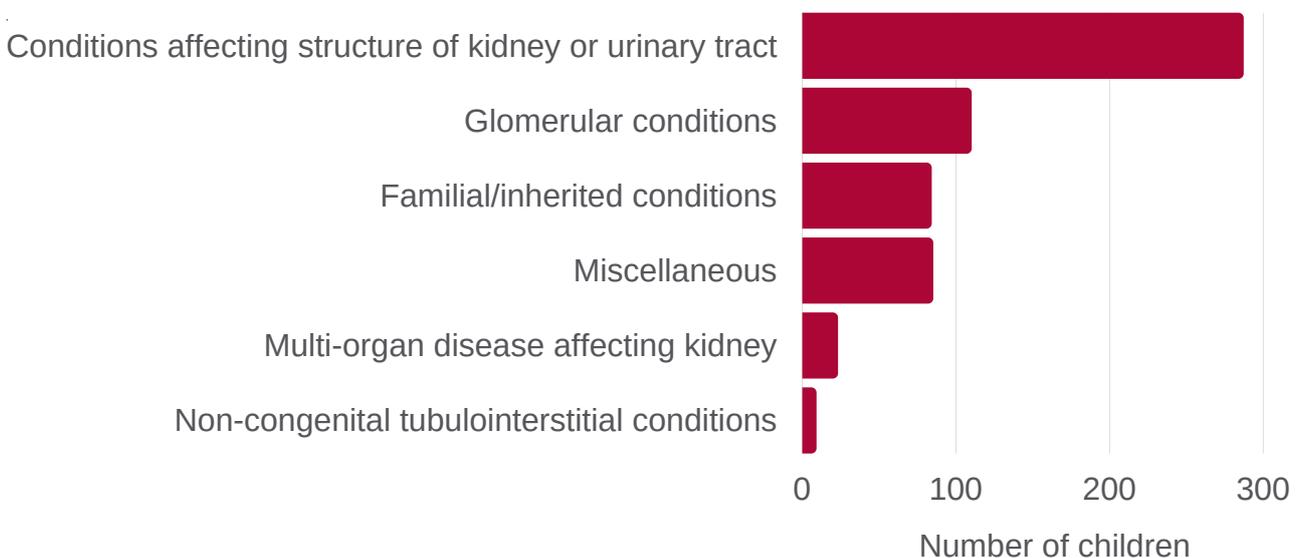


In 2018, 3 in 10 children* first saw a kidney specialist within 90 days of needing to start treatment. This is called late presentation.

Children were under specialist kidney care for an average of 23 months* before needing to start treatment.



Between 2014-2018, half of all children who started treatment had conditions affecting the kidneys or other structures of the urinary tract that were present from birth.

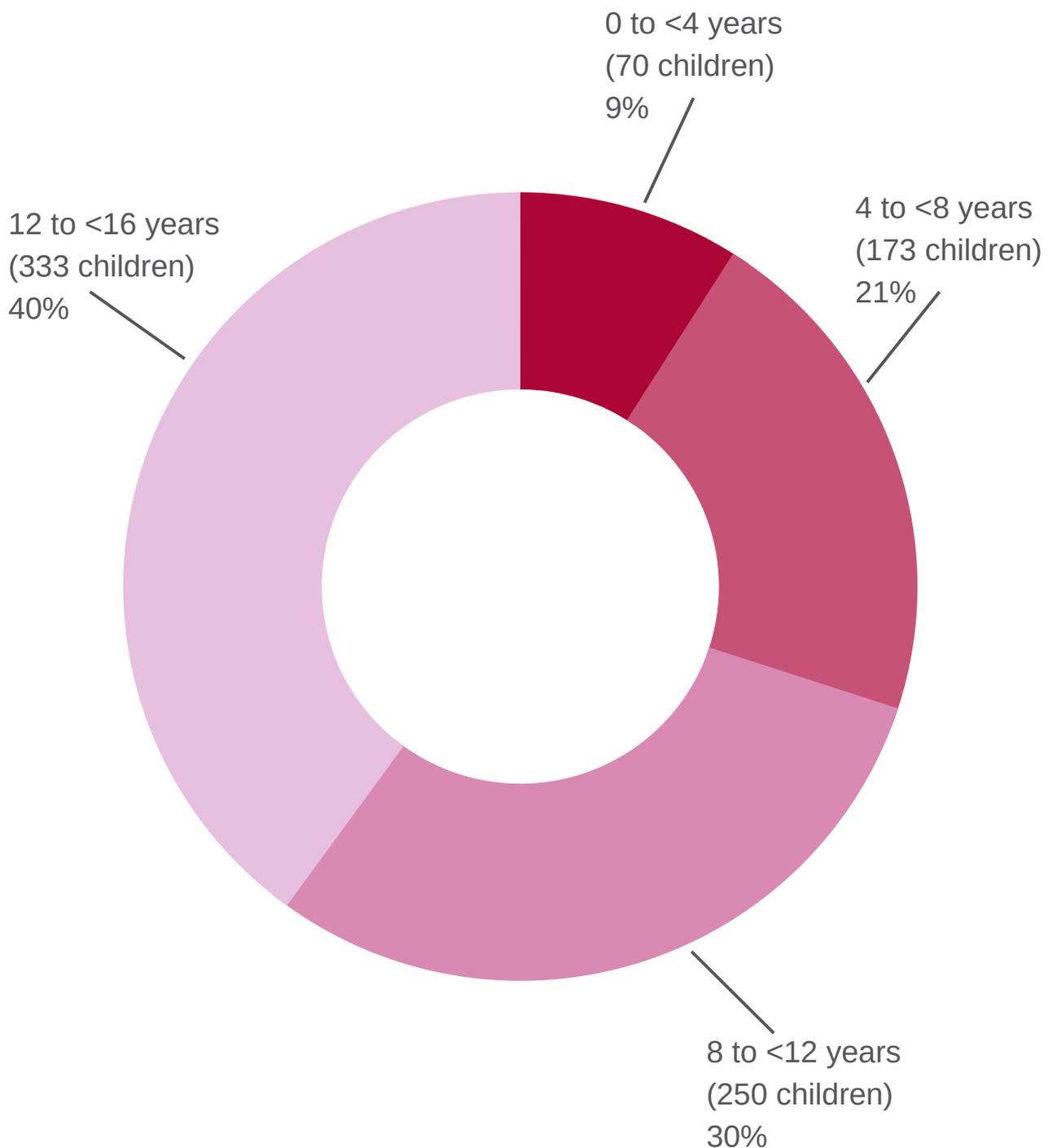


*Based on children with available data.

CHILDREN ALREADY ON TREATMENT

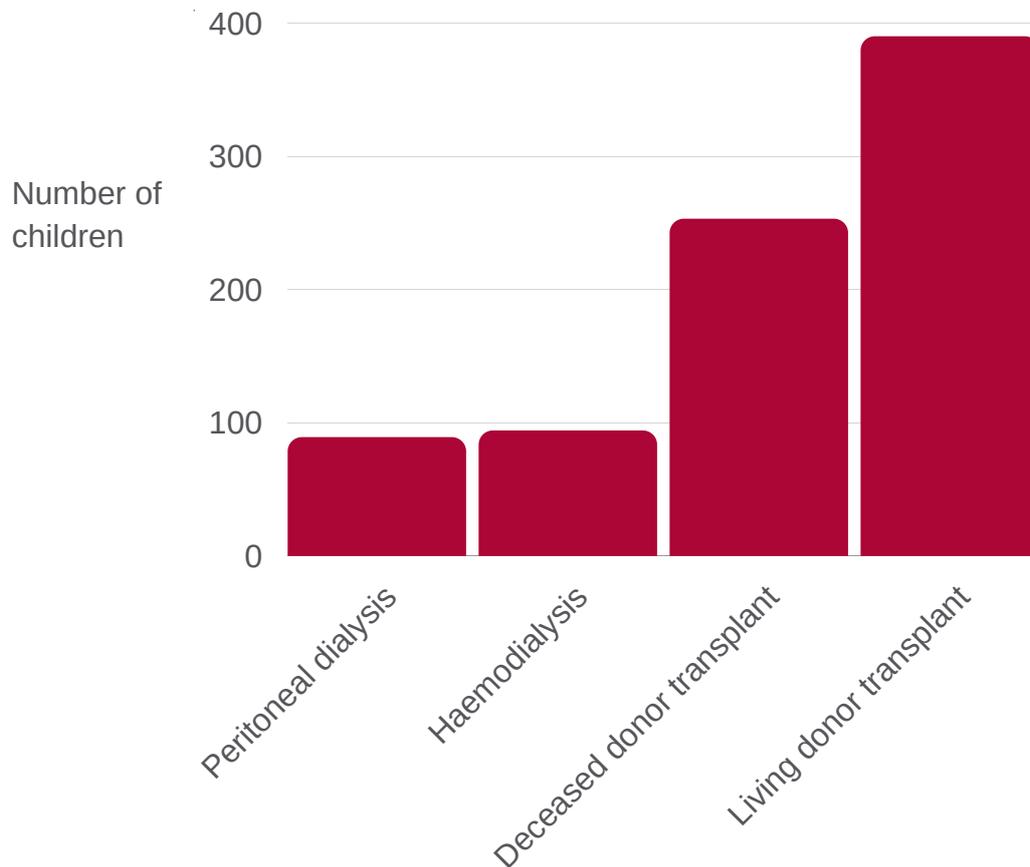
At the end of 2018, 826 children under 16 years of age were on long-term treatment for kidney failure.

Most children on long-term treatment were aged 12-16 years.

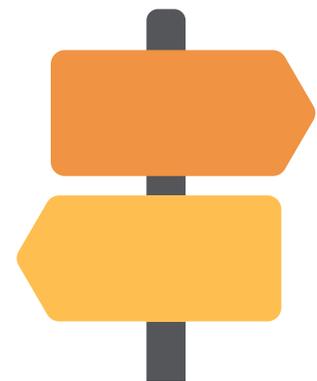


CHILDREN ALREADY ON TREATMENT

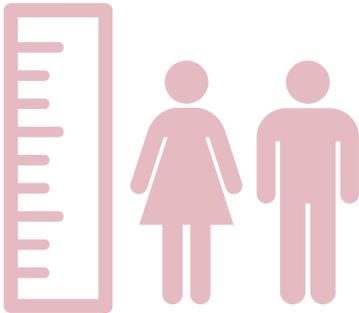
At the end of 2018, most children on long-term treatment for kidney failure had a kidney transplant. The most common was a living donor transplant.



At time of transfer to adult services, most young people (86%) had a functioning kidney transplant.

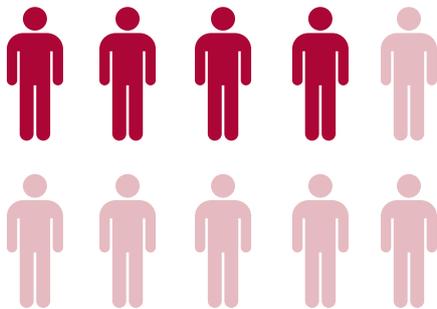
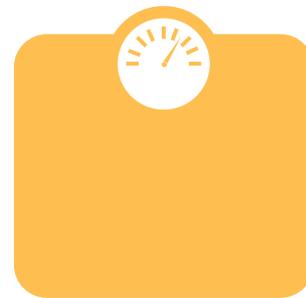


GROWTH AND BLOOD PRESSURE



At the end of 2018, children with kidney failure were shorter than UK children of the same age and sex. This was less pronounced for children who had a functioning kidney transplant.

On average, children on dialysis weighed less than those without kidney failure. Children with functioning kidney transplants had a similar weight compared to the average for their age and sex.



4 in 10 children who received long-term treatment for kidney failure were classified as overweight or obese.

75% of children had systolic and 73% had diastolic blood pressure values within target range*.



*For children under 16 years, blood pressure targets are based on a child's age and height.

CHILDREN WITH KIDNEY TRANSPLANTS

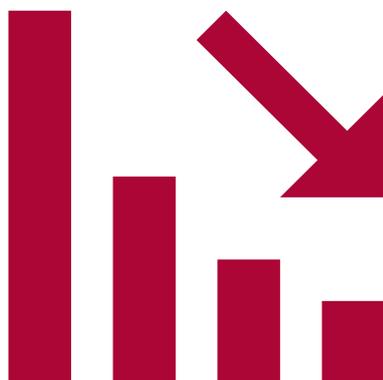


At the end of 2018, 643 children across the UK were receiving long-term treatment for kidney failure in the form of a kidney transplant.

Almost 8 in 10 children who received treatment for kidney failure had a transplant.



The average eGFR* for all transplant patients was 63 mL/min/1.73m².



1 in 20 children had a transplant that was failing, with an eGFR of less than 30 mL/min/1.73m².

*eGFR is a blood test that measures kidney function. In healthy children this typically exceeds 90 mL/min/1.73m².

YOUNG PEOPLE STARTING TREATMENT

For this year's report, both adult and paediatric databases were used to identify total numbers of young people aged 16-18 years on long-term treatment for kidney failure.

In 2018, 18 young people started treatment, which equated to 13 people in every million of the UK young person population.

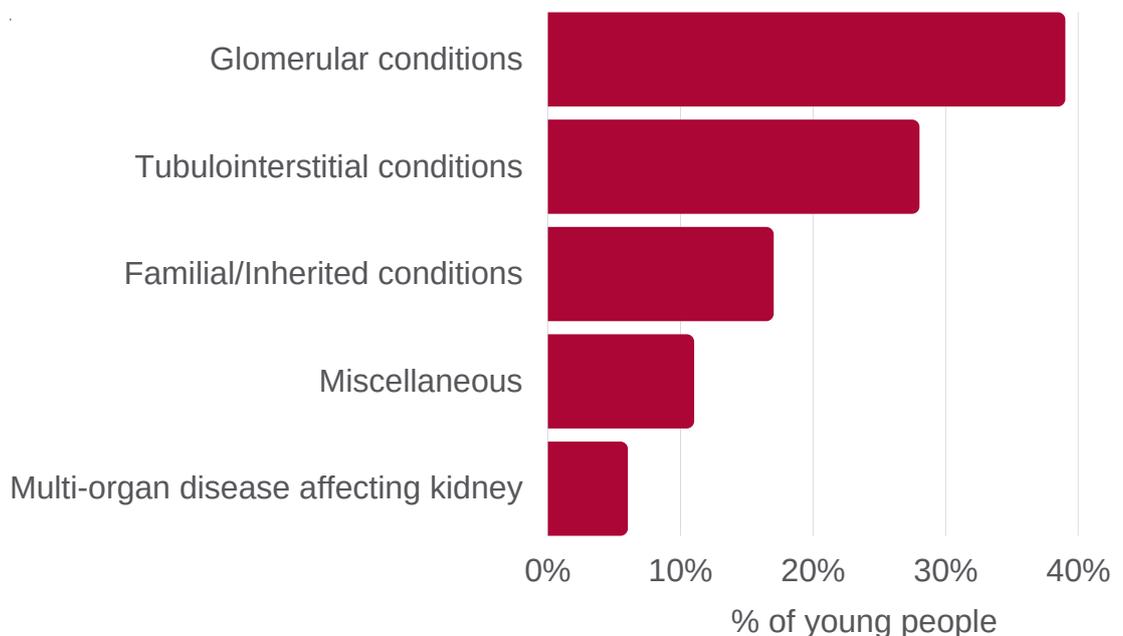


6 were managed in paediatric centres



12 were managed in adult centres

Glomerular conditions were the commonest cause of kidney failure.

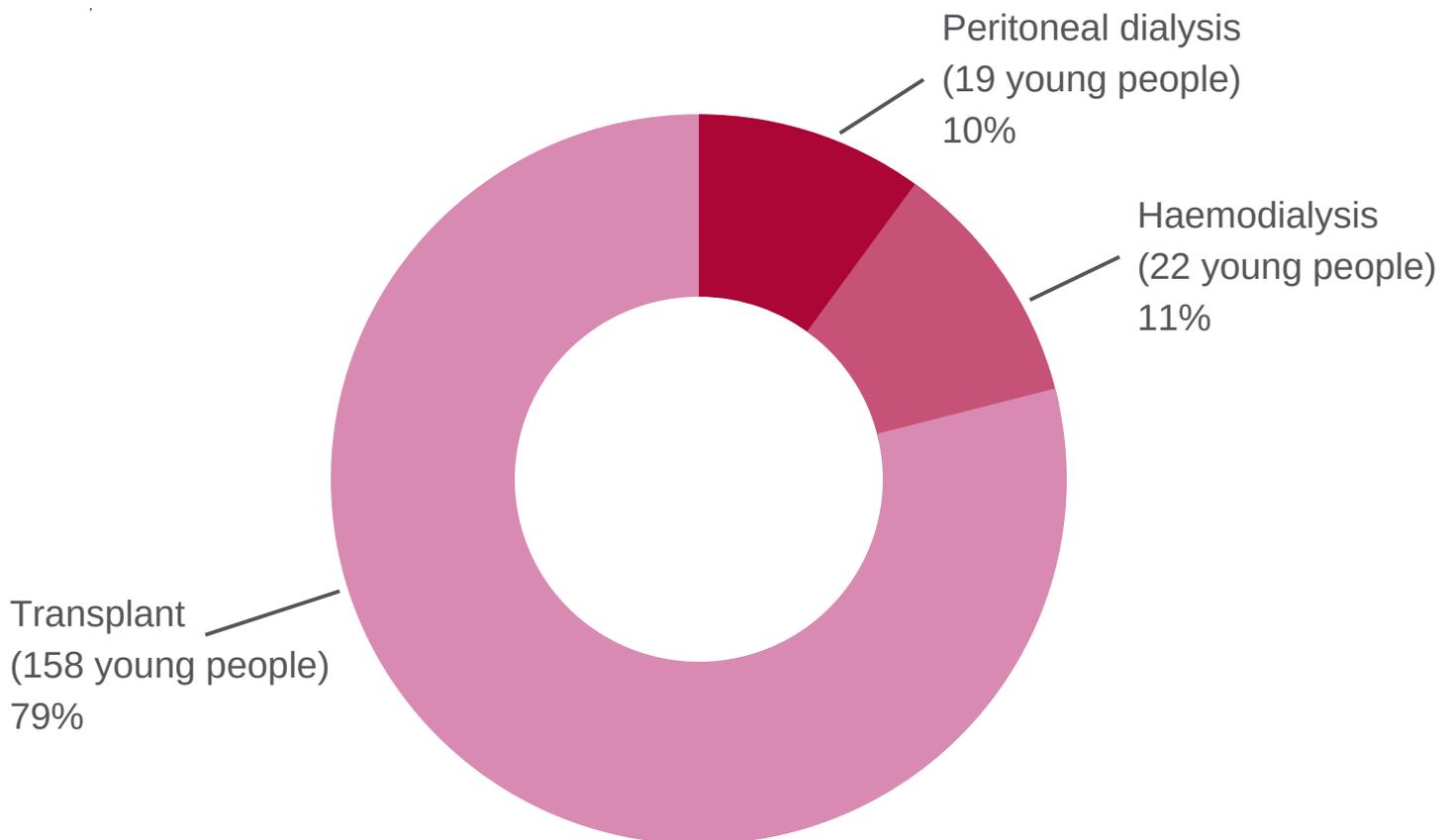


Over a third (39%) of young people who started treatment were male. Most were of White ethnic background (44%), followed by South Asian ethnicity (25%), Other (19%) and Black ethnicity (13%).



YOUNG PEOPLE ALREADY ON TREATMENT

At the end of 2018, 199 young people aged 16-18 years were on long-term treatment for kidney failure: 41 young people were on dialysis, while 158 had a functioning kidney transplant.



For young people with a transplant, the average eGFR* was 72 mL/min/1.73m².

Over half (56%) of young people on dialysis and over two-thirds (70%) of those with a transplant had a blood pressure within the 'normal' range (less than 130/80).



*eGFR is a blood test that measures kidney function. In healthy young people this typically exceeds 90 mL/min/1.73m².

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For more information about this report or about the UK
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