

Donation and Transplantation Plan for Scotland: 2021 - 2026

Equality Impact Assessment

March 2021



Scottish Government
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Policy Aim

An Equality Impact Assessment (EQIA) has been carried out to assess the impact of the Donation and Transplantation Plan for Scotland: 2021-26. The Plan aims, alongside the accompanying UK Strategy, to increase the availability and quality of transplants for patients living in Scotland. After carefully considering the recommendations in the Action Plan, we have assessed many of them as having no discernible different impact on people from equalities groups, although all the recommendations would be expected to benefit those people with disabilities who require a transplant (either directly or indirectly). We have identified particular expected positive impacts for the Race/Ethnicity and Disability protected characteristics from a number of the recommendations. The EQIA process has demonstrated that none of the recommendations are discriminatory.

The Action Plan has been developed taking into account the needs of equalities groups. As noted above, it aims to complement (but not duplicate) the new UK Organ Donation and Transplantation Strategy; that Strategy includes a specific chapter on addressing inequalities of access to transplantation for patients from black, Asian and other minority ethnic communities. That Strategy will be implemented UK-wide. More broadly, ongoing awareness raising work regarding this will be important in explaining what choices people will have and also in helping to increase understanding and support for donation and transplantation.

Who will it affect?

The plan will particularly affect those who are waiting for a transplant or may need one in the future, along with individuals who may become an organ or tissue donor in future and staff working in the fields of either donation or transplantation.

The Donation and Transplantation Plan for Scotland: 2021-2026 aims to build on the improvements in donation and transplantation started following the UK Organ Donation Taskforce report¹ in 2008 and continued through the recommendations set out in [A Donation and Transplantation Plan for Scotland, 2013-2020](#). It covers both living and deceased donation and transplantation of both tissue and organs for adults and children. While there have been significant increases in living and deceased donation over the past decade, progress in some areas has been slower than we would have hoped and our progress in increasing numbers of deceased organ donors has slowed since 2013.

This plan has been developed with the members of the Scottish Donation and Transplant Group (SDTG). In considering actions for inclusion, the group agreed that the plan should focus on those actions which will or are likely to:

- **increase organ and tissue transplantation and improve access to transplantation for patients,**
- **improve the outcomes from transplantation.**

¹ See <https://nhsbtdbe.blob.core.windows.net/umbraco-assets-corp/4245/organsfortransplants/theorgandonortaskforce1streport.pdf>

Key Findings

Race/ethnicity and religion

We know from evidence that kidney failure is up to five times more common in people from Black, Asian and Minority Ethnic (BAME) communities. While it is not yet understood why these communities are more at risk, it could be due to high rates of diabetes and high blood pressure in these racial groups. Asian people with diabetes are ten times more likely to suffer from kidney failure compared to white people with diabetes².

People from BAME communities are more likely to need a transplant, but wait significantly longer on average to receive one due to a shortage of donors. The right tissue type and blood match is vital for a kidney transplant to be successful and the best match often comes from someone with the same ethnicity.

The 2011 census suggests Asian people make up around 3% of the Scottish population, but data from NHSBT indicates that, as at 31 October 2020, they were 9.34% of the active kidney waiting list and 6.4% of the suspended list. For simultaneous pancreas and kidney transplants (SPK) they were 11.53% of the active waiting list and for liver 12.2% and heart 7.7% (there were no people from minority ethnic groups registered as suspended on either of these three waiting lists as at 31 October 2020).

The 2011 census says black people make up around 1% of the Scottish population. For those listed as black, on 31 October 2020 they were 1.87% of the active kidney waiting list and 0.9% of the suspended list living in Scotland so the data again suggests they are proportionately significantly more likely to need a transplant.

Data from NHSBT shows that there were significant differences in the median waiting times in the UK for people joining the kidney waiting list between 1 April 2013 and 31 March 2017. White adults' median waiting time was 573 days, while Asian people waited 736 days on average and black people waited 900 days. Similarly, white children had a median waiting time of 222 days, while Asian children waited 384 days and black children 540 days.

As the statistics show, there is a continued imbalance between the need for transplants in BAME communities and the availability of suitable organs with the right blood and tissue type. Unfortunately only around half as many families from these communities support donation compared to families from a white background. However, the numbers of BAME people becoming more engaged and agreeing to organ donation are increasing. In 2015/16, 5.8% of people from BAME communities who registered their ethnicity opted-in to the ODR and in 2019/20 that rose to 7.8%³.

While this encouraging, there is still work to do to encourage more people from BAME communities to be prepared to donate their organs or tissue. The main

² [Kidney disease in people from Black, Asian and Minority Ethnic communities - Kidney Research UK](#)

³ <https://nhsbtdeb.blob.core.windows.net/umbraco-assets-corp/19753/bame-report-201920.pdf>

reasons BAME families give when saying no to organ donation are concerns about it conflicting with their religious beliefs, and not knowing enough about organ donation, or what the patient would have wanted. Therefore some of the barriers facing ethnic minorities are linked to perceived or actual religious barriers to donation.

Education/awareness raising

The 2013-2020 Plan set out 21 recommendations, grouped under five separate priorities. Some of these recommendations are actions which are expected to continue post-2020, such as: delivering high-profile awareness campaigns on donation and revising the Schools Pack to encourage school pupils to learn about donation.

In particular, the Scottish Government has been working with Kidney Research UK which trains volunteers from South Asian communities to become peer educators to increase awareness of kidney disease and organ donation. This work, along with that of those within the donation workforce with specific responsibility with regards to ethnic minority communities, will continue and will be important in promoting understanding and awareness of living and deceased organ donation among ethnic minority communities. Through the Peer Educator project with Kidney Research UK, there has already been increased awareness of kidney disease amongst South Asian communities in Glasgow and Edinburgh. In addition, this project has been important in raising awareness of the forthcoming move to an opt-out system of organ and tissue donation among members of the Muslim, Hindu and Sikh communities.

Living kidney donation and REACH

A living donor kidney transplant tends to offer patients with renal failure the best outcomes as 89% of adult patients who have a first living donor transplant will still be alive after ten years, compared to around 76-78% of those who have a deceased donor transplant⁴ and 56% of those who stay on dialysis⁵. Data suggests that those currently receiving living donor transplants are proportionately more likely to be white, well-educated and middle class than the general population and people from ethnic minority communities are proportionately less likely to access a living donor transplant⁶. Data from Scottish transplant units indicates that recipients from black, Asian and other minority ethnic groups have made up 3-5% of those receiving living donor transplants between 2017-18 and 2019-20, but they make up over 10% of the waiting list for a deceased donor kidney transplant.

One of the key aims of the Action Plan is that Renal Units should encourage all patients to consider a living donor as their first option if they are suitable for a

⁴ See NHSBT Transplant Activity Report 2019-20 - [section-11-survival-rates-following-transplantation.pdf \(windows.net\)](#)

⁵ Data from UK Renal Registry Report 2018

⁶ See 'Barriers to living donor kidney transplantation in the United Kingdom: a national observational study', 2017 - Diana A. Wu, Matthew L. Robb, Christopher J.E. Watson, John L.R. Forsythe, Charles R.V. Tomson, John Cairns, Paul Roderick, Rachel J. Johnson, Rommel Ramanan, Damian Fogarty, Clare Bradley, Andrea Gibbons, Wendy Metcalfe, Heather Draper, Andrew J. Bradley, Gabriel C. Oniscu

transplant (where it is their first transplant). This will build on the work already being undertaken by Renal Units as part of the Living Donation Scotland work to increase patient and family awareness about living donation, which has led to increases in living donor transplants in Scotland in recent years. In particular, we hope it will encourage more people from those groups less likely to access living donor transplants at the moment, including BAME communities, to be willing to talk to their family and friends about living donation and to accept if a friend or relative does offer to be a donor.

In addition, the Renal Education and Choices at Home (REACH) project is currently being trialled by NHS Lothian. The project involves home visits to people needing a transplant and their key family members to give them more information on living kidney donation. A few Renal Units have also been carrying out or looking into carrying out home visits. The coronavirus pandemic has required NHS Lothian to look at alternative models, such as exploring the potential for these visits to be done via video call.

Subject to the evaluation of the NHS Lothian trial, if it is shown to increase living kidney donation, the Action Plan recommends that it should be rolled out across Scotland to support and encourage open discussion within families and with close friends about choices. This should also benefit some people from ethnic minority communities in supporting them to discuss living donation with close family or friends to help overcome any concerns they have in raising the subject or overcome any misconceptions about what is involved.

Age

In the UK, the median waiting time for a kidney transplant for paediatric patients is 291 days, and for adult patients it is 633 days. Typically, paediatric patients tend to wait less time than adult patients. The organ allocation systems tend to prioritise children because the organ allocation system usually prioritises children, although NHS Blood and Transplant's organ advisory groups are constantly monitoring the allocation algorithms to ensure they are allocating to those with the greatest need. It is also the case that paediatric patients are more likely to access a living donor transplant for kidneys and livers. Data from NHSBT shows that, as at 31 October 2020, there were only thirteen Scottish patients aged 0-20 years on the active transplant waiting list and two on the suspended waiting list (compared to 435 patients in Scotland aged 21-80 years on the active waiting list for a transplant and 352 on the suspended waiting list).

In addition, we anticipate that the recommendations around education and awareness raising, and measures to increase access to transplantation should benefit people needing a transplant regardless of their age. Increased use of novel technologies and work to support research in organ transplantation are already enabling more organs to be used from older donors (with donors in their 70s and 80s now regularly donating organs, such as kidneys, which are successfully transplanted). Developments in research are now in turn also making it more likely that older patients can both be considered for transplantation and undergo a successful transplant. However we recognise that age is not a homogenous group.

Older patients (particularly those over 65 years old) are currently disadvantaged as they are more likely to be suspended from the waiting list for kidneys in particular due to the much higher mortality risk for older patients if they were infected with the coronavirus following a transplant. However, the transplant units hope that these patients can be moved to the active waiting list once they have been vaccinated and so can again be considered for a transplant.

There are therefore not considered to be any differential impacts of the Action Plan for different age groups.

Disability

Almost all patients needing an organ or tissue transplant would have a disability as their organ failure or need for a tissue transplant (such as sight loss) would have a significant impact on their ability to carry out day to day activities. In many cases, patients' long term condition will get worse the longer they need to wait for a transplant and in many cases they will sadly die if they do not receive a transplant. While an organ transplant is not a permanent cure and so patients may still suffer some health impacts or form of disability following a transplant, a successful transplant does enhance patients' lives and make it significantly easier to live with their disability.

Therefore all the recommendations in the Action Plan should have a positive impact on those with disabilities, either by for example helping to reduce the time they need to wait for a transplant (for example as a result of the new opt-out system of donation or greater use of novel technologies), by improving access to living donor transplants for those with kidney failure, by improving the quality of transplanted organs through research and by helping improve the coordination of physical and mental health support for patients after their transplant.

Sex, Pregnancy and Maternity, Gender Reassignment and Sexual Orientation

There is some data available on the sex of transplant recipients, but no information is available around those either waiting for or who have had transplants which would identify information about their pregnancy or maternity status, gender reassignment or their sexual orientation.

There is no evidence to suggest that the recommendations in the Action Plan would affect any of these groups differently from the rest of the population. Therefore, we assume that any measures to increase access to transplantation should benefit people needing a transplant regardless of their sex, sexual orientation or whether they are pregnant, have had a baby or have undergone gender reassignment. There are therefore not considered to be any differential impacts of the Action Plan for these groups.

Conclusion

Having assessed the recommendations in the Action Plan, none of them are thought to have a negative impact on any of the protected characteristics. Several of the recommendations in the Action Plan relate to awareness raising, engaging with harder to reach communities, and improving access to appropriate guidance and support, which we hope will have a positive impact on the race/ethnicity protected characteristics in particular. As noted above, all the recommendations should help improve access to transplant for people with disabilities.

Therefore Scottish Government's key aims are to enable more of those who need a transplant to be able to access timely transplantation and also to use novel technologies and other techniques to ensure that as many transplants as possible work effectively for as long as possible. Alongside this, over the longer term, improving the health of people across Scotland, should reduce the numbers of individuals developing organ failure and needing transplants, which in turn should make it easier for those who do still need a transplant to access one.



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The Scottish Government
St Andrew's House
Edinburgh
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ISBN: 978-1-80004-663-4 (web only)

Published by The Scottish Government, March 2021

Produced for The Scottish Government by APS Group Scotland, 21 Tennant Street, Edinburgh EH6 5NA
PPDAS830067 (03/21)

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