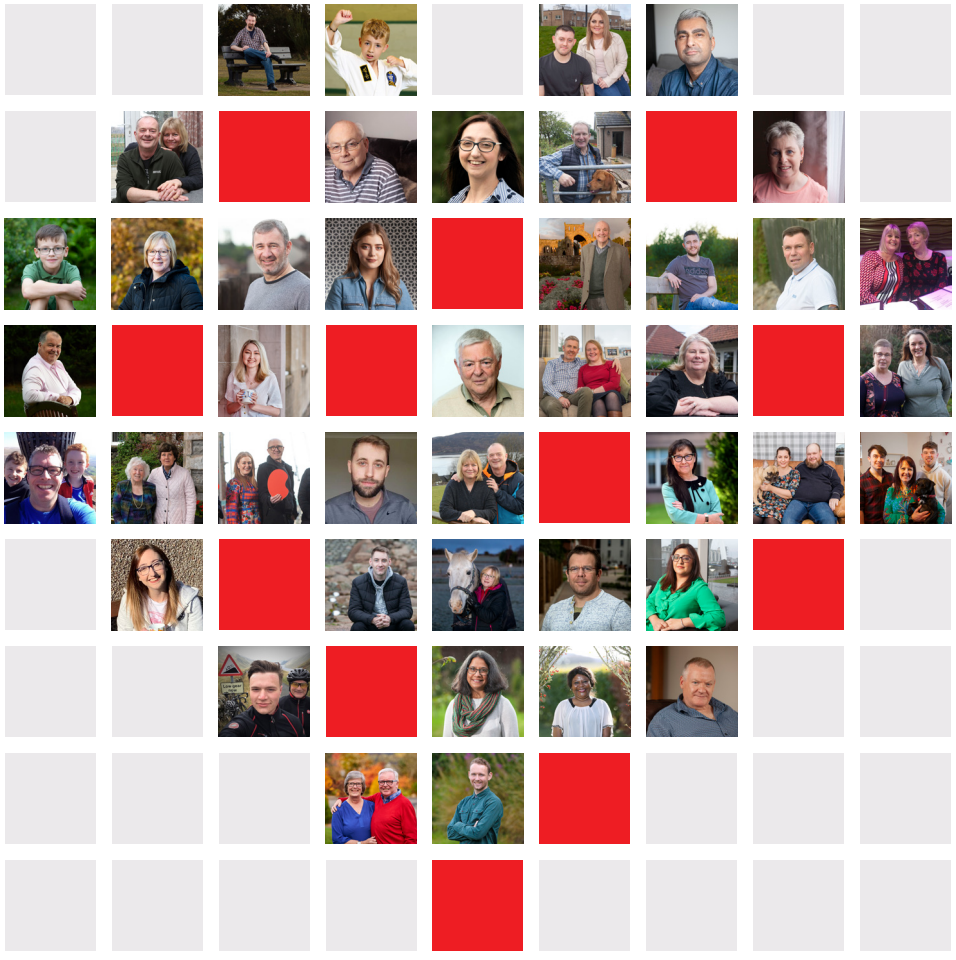
Donation and Transplantation Plan for Scotland: 2021 – 2026



Healthier Scotland
Scottish Government

Contents

Cover image features transplant recipients and living donors from across Scotland.

Ministerial Foreword

The Scottish Government is committed to increasing organ and tissue donation and transplantation to enable more of those people who desperately need a transplant to access one. There are so many inspiring stories of transplant recipients which show us how much of a difference a transplant can make in saving people's lives or significantly improving them. Often, a transplant not only allows people to survive, but to live a full and active life.

Over the last ten years, a great deal of progress has been made, including since our previous Donation and Transplantation Plan was published in 2013. However, there is still a lot more to do. Too many people are still tragically dying waiting for a transplant and too many others are still waiting too long for their transplant, which is not only frustrating for them, but can also have a long-term impact on their health.

There is a high level of public awareness of and engagement with donation in Scotland and public attitudes have changed. Our public consultation in 2016 sought views on increasing numbers of successful donations in Scotland and informed our decision to bring forward an opt-out system of deceased organ and tissue donation. We know the great majority of people in Scotland support organ donation, but sadly many families still don't feel able to support donation when their loved one dies, for a wide range of reasons. As only a very small proportion of people die in circumstances where they could donate organs, every single potential donor is precious.

This new opt-out ('deemed authorisation') system will mean that most adults will be considered to be a potential donor after their death unless they have opted out of donating. There will of course be safeguards to check with family and friends to ensure donation would not have been against their wishes. However, this move should help support a long-term culture change in favour of donation. We want to encourage everyone to think about donation, make a decision and discuss this with their family or friends. This is the best way to ensure everyone's decision can be respected if they sadly die unexpectedly.

Ensuring we can increase the number of deceased donors is part of the solution, but this Action Plan recognises there are many others which, collectively, could make a difference. Improving access to transplants will involve many people and teams across hospitals and the health service more widely, both to increase numbers of donors and to ensure we make best use of all the organs and tissue that are donated. In particular, we need to take advantage of the novel technologies which can really help ensure more organs can be used and are more likely to work effectively for longer once transplanted.

For kidney patients, it's also vital to remember that a living donor will normally offer the best outcomes for a person's long-term health. So we want to support patients and their families and friends as much as possible to find a suitable living donor for them. There has already been good progress in increasing numbers of living donors coming forward, but we want to see this continue to grow. While opt-out should help reduce waiting times, there are so many people waiting for a kidney transplant that we need living donors, as well as deceased donors, to support all those needing a transplant.

I am very grateful to colleagues in the Scottish Donation and Transplant Group and more widely across NHS Boards in helping to develop this action plan. The Scottish Government is confident that, through the package of measures described in the plan – both new recommendations and initiatives already started – we can significantly increase the numbers of transplants over the next five years.

Mairi Gougeon MSP, Minister for Public Health and Sport

Background

Introduction

This plan aims to build on the improvements in donation and transplantation started following the UK Organ Donation Taskforce report[1] 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 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.**

Increasing the numbers of donors and organs and tissues donated will be a key part of the plan, along with increasing the number of available organs that can be used for transplant. The Human Tissue (Authorisation)(Scotland) Act 2019 is implementing an opt-out system of authorising donation as a key part of our objective of increasing authorisation rates, and therefore in turn numbers of deceased donors, in Scotland. 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.

This plan complements the UK Organ Donation and Transplantation Strategy and supports its objectives. Similar to the UK Strategy, we set out here our aims for the next decade, although given how much may change over that decade in this area, we have focused on recommendations which we anticipate can be delivered or where we can make significant progress in the coming five years. Work on public health promotion in particular though will take longer. This plan seeks to avoid duplicating actions already covered in the UK Strategy, particularly where actions are best taken forward on a UK-wide basis, and therefore the two documents should ideally be read together. However, this action plan does set out a number of additional Scotland-specific actions to be taken forward.

In addition, both this plan and the UK Strategy will inform the development by NHS National Services Scotland's National Services Division (NSD) of a commissioning plan for organ transplantation for patients living in Scotland. This new plan will look at the

[1] See https://nhsbtdbe.blob.core.windows.net/umbraco-assets-corp/4245/organsfortransplantstheorgandonortaskforce1streport.pdf

resources needed to deliver the likely demand for transplants and will succeed the existing plan – Commissioning Transplantation to 2020[2]. NSD is in the interim also working on a shorter term plan to focus on responding to the challenges of coronavirus in relation to transplantation.

While we hope that Scotland and the rest of the world will soon ensure the SARS-CoV-2 coronavirus infection is under control, we need to reflect on some of the lessons learned during 2020 to ensure this Plan takes account of the fact that the virus may continue to impact on NHS services and pose risks to patients for some time to come. We have also reflected on some of the changes made by necessity due to the virus, which may benefit patients in the longer term, such as ensuring greater use of video call technology.

An Equality Impact Assessment also accompanies this Plan and will aim to ensure that this Plan, alongside the UK Strategy, will support individuals who may have one or more of the protected characteristics. In particular, it will seek to ensure that the recommended actions will help improve outcomes in particular for disabled people and people from black and minority ethnic communities.

Achievements from the 2013-2020 Plan

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, continuing targeted awareness-raising with minority ethnic (particularly South Asian) communities, revising and keeping the Schools Pack up to date and training days for Procurator Fiscal staff.

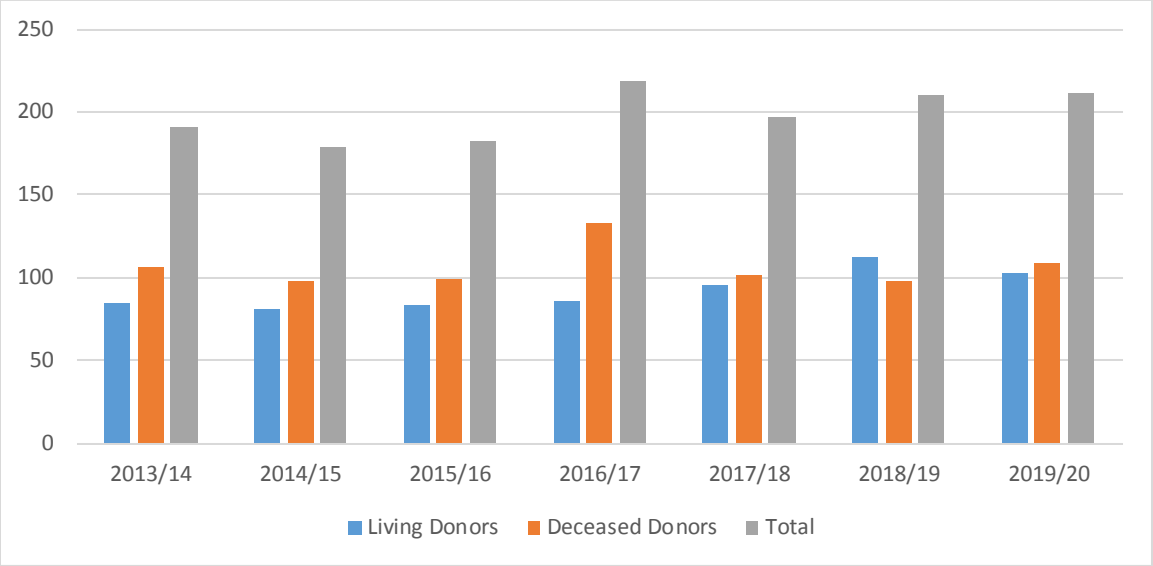
Most of the recommendations are either complete or ongoing (for example, some require annual publications or awareness raising, but are essentially now part of the day to day approach to donation). However, there are a few recommendations where implementation is not yet finalised or has not progressed. In particular, for recommendation 10, we will continue to encourage closer working with the island NHS Boards and more remote hospitals to ensure people living in those areas and NHS staff have awareness about deceased donation and so opportunities for transferring potential donors to other hospitals could be considered, where appropriate, in discussion with a patient's family.

A small number of the recommendations are no longer being progressed. For example, recommendation 7 - the Category II Donation after Circulatory Death (DCD) pilot for patients experiencing cardiac arrest outside a hospital is no longer continuing. However, it could potentially be reconsidered in future if appropriate, learning lessons from the pilot evaluation. In addition, the Scottish Government explored with NHS Grampian the potential for piloting a 'whole hospital' approach to donation. This was not ultimately progressed, although recommendations from the review of Organ Donation Committees (recommendation 17) are already encouraging all mainland NHS Boards to take a whole hospital approach to organ and tissue donation involving a wide range of teams and Departments across their hospitals; as a result, it was felt a pilot was no longer necessary.

[2] See https://www.nsd.scot.nhs.uk/publications/Servicereviews/CTT2020%20final%20report.pdf

Chart 1 below shows that some progress has been made in increasing living donor numbers over the course of the 2013-2020 Plan, while numbers of deceased donors have remained fairly constant overall.

Chart 1 – Organ Donor Numbers in Scotland 2013 – 2020

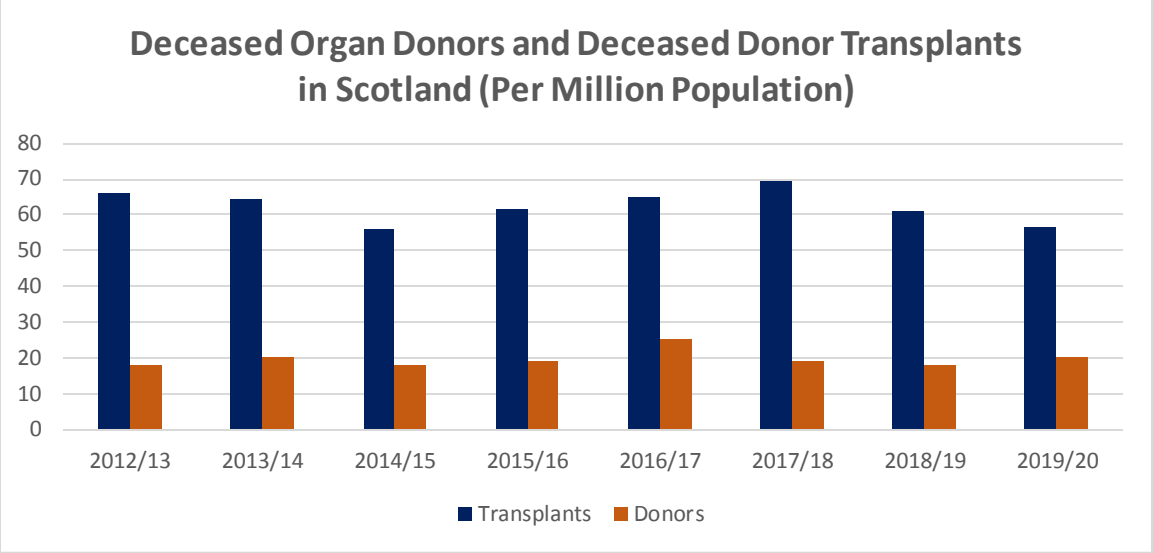


In addition, the 2013-2020 Plan set out ambitious targets for donation, transplantation and authorisation rates. It aimed by 2020 to achieve the following targets in Scotland:

- Overall deceased donation rates would increase from 17.9 per million population in 2012/13 to **26 per million population**.
- Overall transplantation rates in Scotland from deceased donors would increase from 65.8 to **74 per million population**.
- Family authorisation rates in donation after circulatory death (DCD) would increase from around 50% **to around 80%**.
- Family authorisation rates in donation after brainstem death (DBD) would increase from around 78% **to around 85%**.

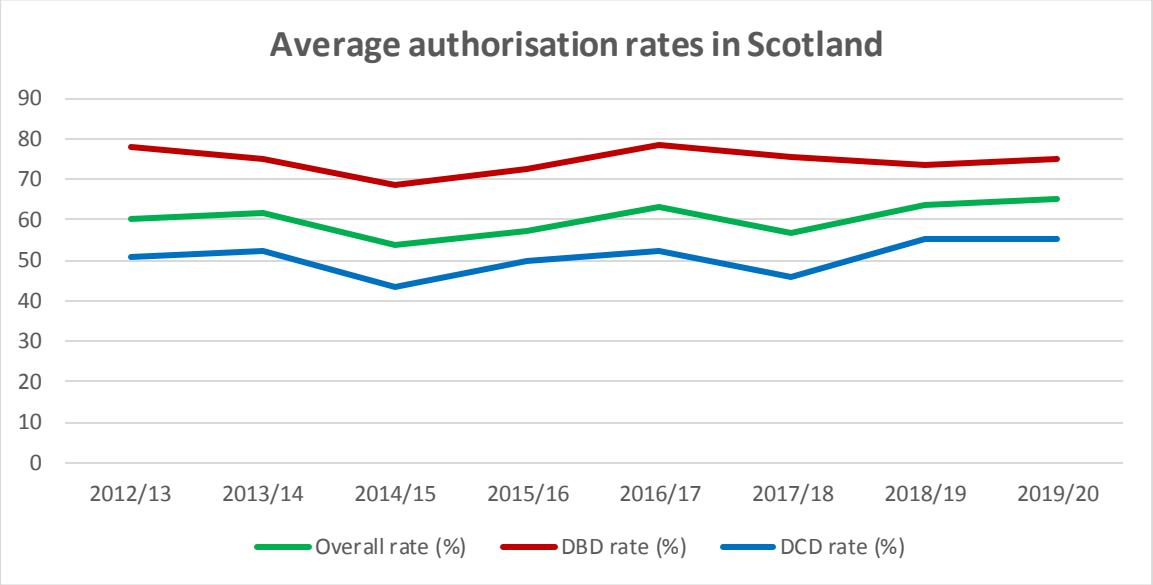
Charts 2 and 3 below show that we have made progress in some areas and in some years, but have unfortunately not achieved the ambitious targets which were set.

Chart 2



Source – NHSBT

Chart 3



Source - NHSBT

We will continue to monitor these rates throughout the period covered by this Action Plan and our aim will still be to see increases in all these figures over the next five years. However, donation and transplantation rates, along with authorisation rates, do fluctuate constantly for a wide range of reasons, many of which are outwith the control of NHS staff. Therefore, we have not set separate Scottish targets for the Action Plan period.

This Plan sets out seven key priority areas covering a range of areas of both living and deceased donation and transplantation, with recommended actions grouped under each of these sections.

Priority One – Implementation of the Human Tissue (Authorisation) (Scotland) Act 2019

Authorisation is an important factor which affects whether donation, and ultimately transplantation, can proceed. Presently, Scotland has the highest proportion of people registered on the Organ Donor Register in the UK (49%), but surveys show that even more people living in Scotland support donation. This suggests therefore that many people who support donation simply do not get round to registering their decision.

Additionally, each year a proportion of families refuse authorisation for their loved one's organs to be donated. In 2019-20, in 35% of cases in Scotland where family members were approached about deceased organ donation, authorisation was not given or (in a few cases) the family overrode the authorisation the person had previously given. It is important therefore to look at ways which will ensure that individuals who would want to donate are able to do so.

Following public consultation and evidence of a shift in public attitudes towards support for an opt-out system of organ and tissue donation, the Scottish Government introduced legislation to the Scottish Parliament providing for such a system. Following Parliamentary support, the Human Tissue (Authorisation) (Scotland) Act 2019[3] (which amends the Human Tissue (Scotland) Act 2006) was passed and will be implemented in March 2021. The primary aim of the Act will be to introduce a system of deemed authorisation (opt-out) for deceased donation for transplantation.

International evidence suggests that opt–out legislation can be effective as part of a package of measures to increase donation. Whilst there is insufficient evidence to conclude that opt –out legislation alone will increase donation, evidence highlights the importance of non-legislative measures which can work effectively in their own right to increase donation and transplantation and which are often associated with successful opt-out systems. The introduction of the opt-out system in Scotland should be seen in this context.

The Act also provides a legislative framework for carrying out medical procedures and tests prior to a potential donor's death to facilitate successful transplantation. This framework means that there are clear processes in place supported by specific requirements which must be satisfied before these procedures are carried out.

Public Information

1.1 Public awareness of organ and tissue donation has grown over the last 12 years as a result of the duty on Scottish Ministers to support and promote donation in Scotland. The 2019 Act builds on those duties by requiring Scottish Ministers at least once in every calendar year to provide information to the public about how authorisation may be deemed to be given, how to make an express authorisation to donate and how to make an opt-out declaration. The knowledge of the public of the new system will be important in supporting informed decisions on donation and we will ensure the information provided is accessible as possible.

[3] http://www.legislation.gov.uk/asp/2019/11/contents/enacted

In the lead up to the introduction of the new system, amongst other information routes, every household in Scotland will receive an information leaflet. This will be supplemented by a fully accessible public information campaign, delivered via a range of media, such as television and radio advertising and social media.

There will also be detailed information available on the Organ Donation Scotland website for anyone who wants to find out more, along with a focus on providing bespoke information for certain groups, such as Easy Read materials for individuals with learning difficulties, specific leaflets for people from a number of different faiths and leaflets available in a number of different languages. Linked to NHSBT's programme to develop a network of organ donation 'ambassadors', the Scottish Government will also be looking to coordinate how we make good use of the many committed volunteers who already make an important contribution to awareness raising and helping people to understand the benefits of organ and tissue donation. Many transplant recipients, along with peer educators and some donor family members, already give up their time to speak to groups about donation; hopefully we can support them to widen the reach of our awareness raising.

Training for Specialist NHS Staff

1.2 We will work to increase awareness amongst specialist NHS staff of the deemed authorisation legislation, as well as (where applicable) the requirements of the new statutory framework for pre-death procedures (PDPs). Alongside the detailed guidance for staff on the requirements of the legislation, a programme of training will be rolled out for Specialist Nurses for Organ Donation (SNODs), Tissue Donor Coordinators (TDCs), Clinical Leads for Organ Donation, other key medical and nursing staff who refer and care for potential donors, and retrieval teams. Organ Donation Committees will also be asked to support the implementation of the opt-out legislation by raising general awareness more widely across staff in their NHS Board area. This will help ensure that staff who do not have direct involvement in donation are still able to answer key questions or know who to pass queries on to if patients or their families raise questions about organ or tissue donation.

Evaluation of Deemed Authorisation

1.3 In line with the requirements of the Act, the Scottish Government will undertake an evaluation of the deemed authorisation legislation and publish a report on the evaluation at the end of five years following implementation of the opt out system. The evaluation will examine the effectiveness of the law change, by monitoring public awareness and whether public attitudes have changed as a result of the law change; monitoring authorisation rates and evaluating whether the legislative change appears to be operating effectively and whether it has had any negative impacts. The conclusions reached in the evaluation report will be considered by both the Scottish Donation and Transplant Group (SDTG) and Scottish Ministers to inform practice and continue work to improve outcomes for donation and transplantation.

Pre-death Procedures (PDPs)

1.4 In setting out a legal framework for authorisation of pre-death procedures it is recognised that medical science and processes are constantly progressing. Therefore the Act provides for the amendment of the regulations which support the framework for carrying out pre-death procedures.

We will ensure that clinicians are aware of how to refer any proposals for changes to the regulations to the Scottish Government. It is intended that proposals for amendment of the regulations would be considered by a sub-group of the SDTG, taking advice from bodies such as the Research, Innovation and Novel Technologies Advisory Group (RINTAG) and others with specialist expertise on the proposed procedure(s) to consider whether the proposed changes should be recommended to Scottish Ministers. Such changes would be subject to consultation before regulations are laid for scrutiny by the Scottish Parliament.

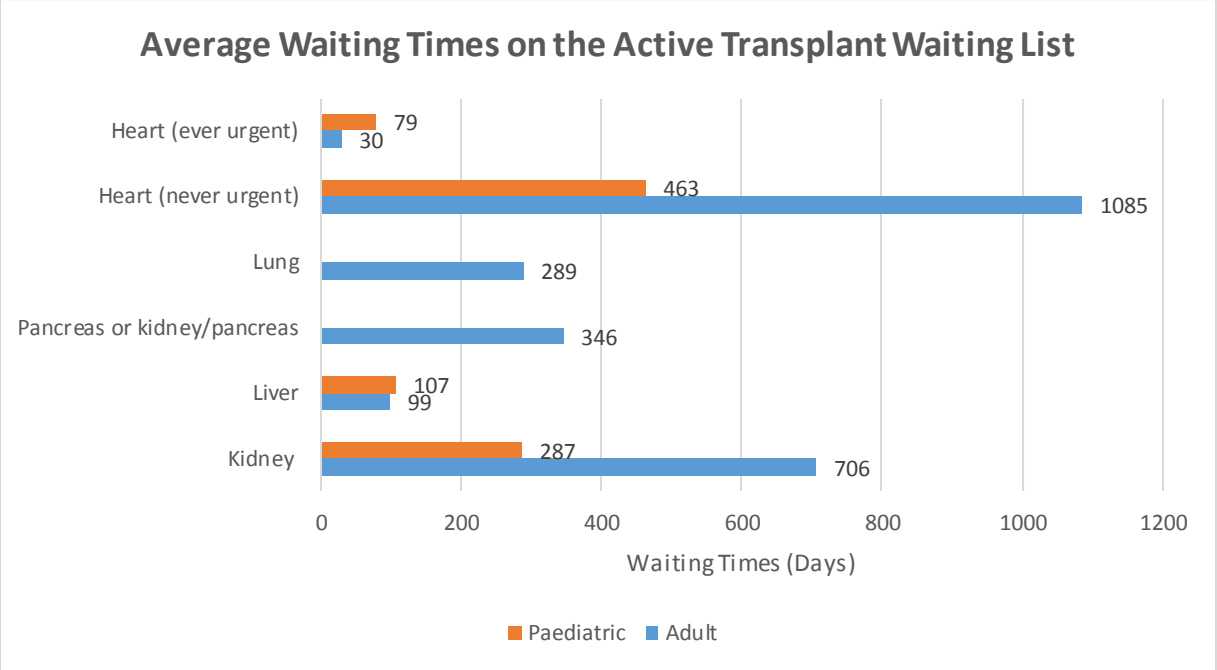
Key Recommendations		Short term 1 – 2 years Medium term 3 – 5 years	Lead
1	Raise awareness across Scotland about the change in legislation, aiming to reach as many people as possible, including harder to reach groups.	Short term, although regular awareness raising will continue following introduction of deemed authorisation.	Scottish Government
2	Ensure key staff likely to be involved in approaching families about deceased donation receive training and guidance on the new legal requirements in relation to deemed authorisation and pre-death procedures. Also put in place wider general awareness raising for other NHS staff.	Short term – to be delivered by March 2021.	Scottish Government, with support from Clinical Leads and Organ Donation Committees
3	Undertake an evaluation of the deemed authorisation system and seek to learn any lessons from the evaluation findings.	Medium term – expected by 2025-26.	Scottish Government
4	Keep pre-death procedures regulations under review. If changes to either Type A or Type B regulations are proposed, ensure these proposals can be considered and, if appropriate, amendments can be made.	Short to medium term.	Scottish Government

Priority Two – Increasing Organ Transplantation

We want to continue to increase the number of transplants for Scottish patients, reduce waiting times and provide the best possible outcomes for patients.

We aim to support the use of novel technologies and closer joint working between transplant units to increase organ utilisation. We also need transplant units to continue working with all NHS Boards to increase equity of access to transplantation across Scotland, making sure that organ failure is diagnosed early wherever possible and that factors such as where someone lives doesn't affect their chances of being referred for a transplant.

Chart 4



Note - data above provides median waiting times in days on the active transplant waiting list – registration periods vary by organ. For 'ever urgent' hearts, data is for the time the patient was on the urgent waiting list only. Data from NHSBT Transplant Activity Report for 2018-19[4].

As Chart 4 above shows, average waiting times vary significantly by organ and waiting times will also vary depending on how urgently they need a transplant. In many cases, waiting times are still too long and patients risk significant deterioration in their health and even death while they wait. In addition, some groups, such as people from black and minority ethnic communities, tend to wait longer than average as their best chance of a good organ match generally comes from a donor of the same ethnicity.

The new opt-out systems of deemed authorisation (or consent) in both Scotland and England are expected to increase the number of deceased organ donors over

[4] See https://www.organdonation.nhs.uk/helping-you-to-decide/about-organ-donation/statistics-about-organ-donation/transplant-activity-report/

the coming years. This provides a real opportunity as more organs are expected to be offered to Scottish transplant units. Therefore, it is important that units are able to make use of all of those organs which are considered suitable for transplant.

While transplant units do receive a lot of organ offers, the majority of these organs are not able to be transplanted. However, the great majority of organs that are declined are not transplanted by any other transplant unit. There are a range of reasons why organs are not accepted by a centre (and in many cases, there may are a combination of reasons, rather than just one factor). However, the most common reasons recorded relate to concerns about the donor or the organ/its function; this could include factors such as the donor's age, BMI or past medical history or evidence from tests (such as X-rays), suggesting the organ does not have good function levels. While many of these factors may always rule out certain donors from ever being suitable to donate particular organs, novel technologies in particular offer the opportunity to allow transplant units to use more 'marginal' organs that may currently need to be declined.

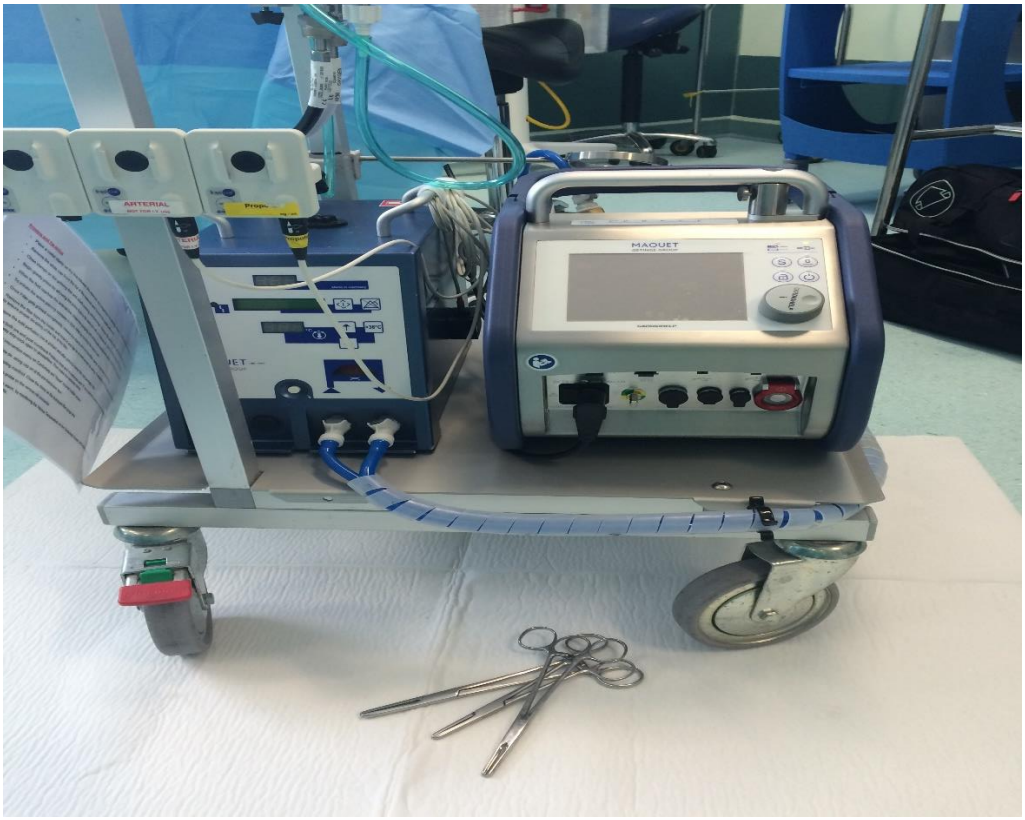
SDTG will continue to monitor reasons for organs being declined and, in particular, consider with units where organs have had to be declined for logistical reasons. Data suggests that relatively small numbers of organs are declined due to hospital issues, such as no beds or operating theatre being available. However, in 60 cases in 2019, records suggest organs had to be declined primarily because the transplant unit was already retrieving or transplanting organs at the same time. As well as needing to consider units' capacity as part of National Services Division's future commissioning planning, this also highlights the potential for machine perfusion technologies to help reduce the need for those organs to be declined in future by allowing a longer time period between the retrieval and when the organ needs to be transplanted.

Increasing the number of viable organs for transplantation and improving transplant outcomes

2.1 We will support the commitments in the UK Strategy to continue to promote developments in perfusion technology and to implement these when there is evidence to support them being sufficiently safe and effective. The Scottish Government has already committed to funding its share of costs of a full UK roll out of use of Normothermic Regional Perfusion (NRP) for abdominal organ retrievals for all donors donating after circulatory death (DCD donors). There is evidence from liver retrievals in particular that using NRP both improves the quality of the organ, thereby reducing the risk of graft failure or complications post-transplant. NRP also increases the number of organs which are transplanted as organs which units would otherwise decline as being too risky can go through a period of assessment. We will work with NHSBT and the other UK governments to try to ensure the use of NRP can be more widely used as soon as practicable.

We will also monitor the progress of the current three year initiative funded by NHSBT and NHS England to enable the retrieval of more hearts from DCD donors. If this is effective in increasing heart transplant access for Scottish patients, we will consider with NHSBT and the other UK governments the potential for a longer term roll out of a DCD heart donation programme. Alongside this, the impact of retrieving hearts from DCD donors for potential solid heart transplant on the availability of heart valves in Scotland

will also be monitored. At the present time, it is considered unlikely that there will be a significant impact on heart valve donation numbers as we expect that only a small proportion of DCD donors will be suitable heart donors (Priority Three sets out other actions to help increase the numbers of heart valves donated).



Picture of NRP machinery – courtesy of NHS Lothian

Alongside similar work in the UK Strategy, we will support work to increase the use of ex-vivo Normothermic Machine Perfusion (NMP) which allows organs to be perfused after they have been removed from the donor and kept oxygenated for longer before transplant. We will consider with transplant units and National Services Division (NSD) the feasibility of an organ reconditioning hub for Scotland (known as an Assessment and Recovery Centre or ARC) to centralise abdominal ex-vivo organ perfusion services. An ARC would hopefully help increase the number of transplantable organs and enable units to stagger the timing of their transplants better. Subject to the outcomes of the feasibility study, in due course, a proposal to trial reconditioning of livers at the Scottish National Blood Transfusion Service's (SNBTS) headquarters will be considered. If successful, this ARC could also be used for the management of kidneys, pancreata and lungs in due course. This work is still at a fairly early stage, but it would have the potential to provide a service for a number of transplant units. SNBTS has already developed expertise in the field of Advanced Therapy Medicinal Products (ATMPs) and may be able to use this expertise in the future to use cell and gene therapy to help regenerate organs for transplantation.

Work to ensure a sustainable, patient-centred transplant service in Scotland

2.2 National Services Division's (NSD's) future commissioning plans will look at ensuring transplant units have the capacity to deliver the anticipated gradually increasing numbers of transplants over the coming five years. SDTG will continue to work with

NHSBT to monitor organ utilisation in Scotland and in particular the reasons for any organs being declined due to lack of capacity. We will support the UK Strategy in continuing to monitor and discuss with units any significant variations in practice on organ utilisation (where these are not explained by some units using novel technologies) to try to encourage good practice.

To support this, we propose that NSD should work with the transplant units to explore options for the sharing of services and resources and increased collaboration between Scottish units. Work to explore increased collaboration has already begun between the Edinburgh and Glasgow adult renal units. This could also help ensure transplant units learn from one another's experiences and potentially support each other to ensure equity of access to transplant services across Scotland.

With the potential increase in the number of viable organs for transplantation, the Scottish Government and NSD also need to support transplant units and the British Transplantation Society in their work to ensure sufficient and sustainable staffing levels in future. In addition, we also need to work with NHS Boards to ensure appropriate, secure IT is in place to allow both transplant units and referring clinicians to be able to access and share patient information more easily. This can be an issue for both adult and paediatric services. While clinicians can access patient records for patients living in their own NHS Board area, it is often more difficult, particularly out of hours, to get the necessary access to records of patients living in other Board areas.

Ensure that all patients likely to benefit from transplantation are offered the opportunity

2.3 We will seek to increase equity of access to transplantation services across Scotland by reviewing current and projected need for referral to transplant units, in particular looking at any significant variations in referral rates between NHS Boards. Transplant units in partnership with NHS Boards will be asked to continue to increase awareness of transplant services with referring clinicians across Scotland, particularly focussing on any areas with referral rates significantly below the Scottish average. Clinicians and NHS Boards should be encouraged to ensure they proactively identify and discuss transplantation with any patient who may be eligible for and benefit from a transplant. We will explore the potential for developing a network of clinicians who can support improvements within Boards and ensure key staff are kept up to date with developments in the field of transplant.

Key Recommendations		Short term 1 – 2 years Medium term 3 – 5 years	Lead
1	Increase the number of viable organs for transplantation by using novel technologies, such as rolling out use of machine perfusion. Subject to the findings of initial feasibility work, consider moving ahead with development of a Scottish Assessment and Recovery Centre.	Medium term	NHS Lothian/ SNBTS, NHSBT and Scottish Government

2	Work to ensure sustainable, patient-centred transplant services, including exploring options for increased shared services between renal units, in particular to avoid the need for patients to miss out on any suitable organs offered for them.	Short to medium term	NSD and Transplant Units
3	Raise awareness among relevant staff across NHS Boards to seek to ensure all those patients who would be likely to benefit from a transplant are offered the opportunity.	Short term	Transplant Units, NHS Boards, supported by SDTG

Priority Three – Reducing Missed Opportunities for Deceased Donation

We want to continue to ensure that, wherever possible, anyone who would have wanted to donate can have that decision respected when they die.

Chart 5

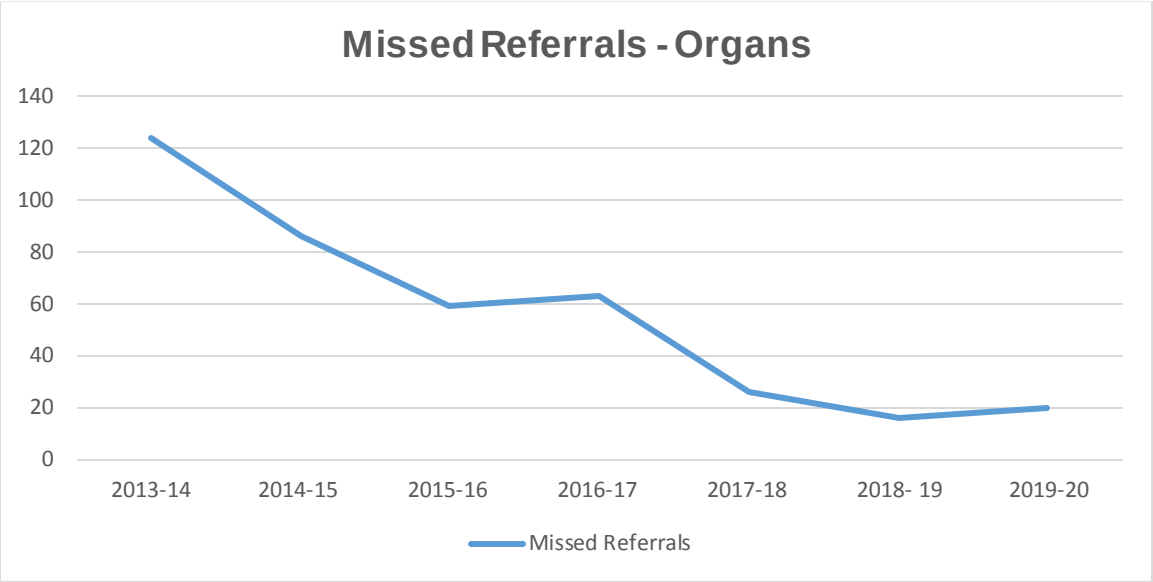
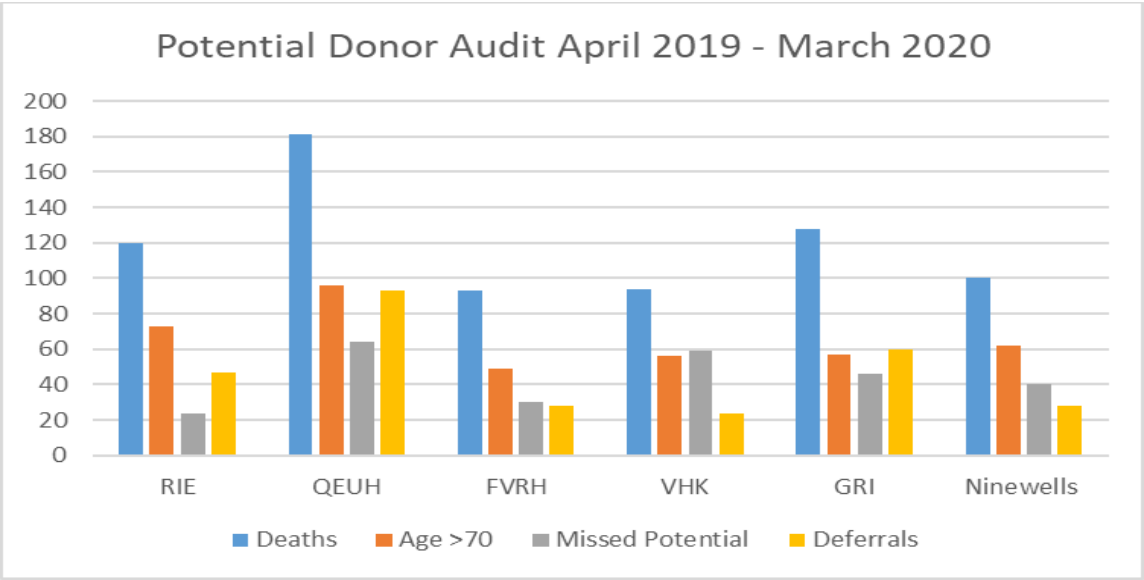


Chart 6

Missed Referrals – Tissue



The chart above sets out data on potential donors and missed referrals (in grey) at six main tissue-donating hospitals: the Royal Infirmary of Edinburgh, the Queen Elizabeth University Hospital, Forth Valley Royal Hospital, Victoria Hospital Kirkcaldy, Glasgow Royal Infirmary and Ninewells hospital. Of the 716 patient deaths audited across the five hospitals, 263 patients (36.7%) were considered to be missed potential donors with no documented consideration regarding donation.

Good progress has already been made in reducing missed referrals of potential organ donors, but there is a need to continue working with NHS Boards and their Organ Donation Committees to ensure there are no missed opportunities for either organ or tissue donation. Organ Donation Committees are required to prepare an action plan annually, focussed on any identified areas for improvement, so this should include avoiding missed referrals where this has been an issue. We also need to avoid opportunities for eye donation being missed due to a lack of available retrieval staff; the Scottish National Blood Transfusion Service (SNBTS) is just starting to deliver the eye retrieval service across the central belt, which should enable an increase in eye donation. NHSBT is also continuing to make progress in ensuring that a Specialist Requester or SNOD is always involved in approaches to family members about donation.

It will also be important to ensure that, in line with the opt-out legislation, decisions on whether donation is authorised focus on the decisions made by the potential donor – whether that was to opt in by joining the Organ Donor Register (ODR), to opt out or to do nothing (which, as is being highlighted to households, will also be treated as a decision to opt in in most cases). We anticipate that the new Specialist Requesters who have now started leading approaches to families about organ donation in almost all cases will help to increase authorisation rates in Scotland and to reduce the number of occasions where a potential donor's authorisation decision is overridden by their family.

Authorisation for Organ Donation

3.1 It is anticipated that using the Specialist Requester model will help ensure the best possible chance of delivering improvements in authorisation rates through the introduction of deemed authorisation. As the diagram on page 18 shows, only a small proportion of people die in circumstances where they could donate organs; it is therefore important to ensure as many of these potential donors as possible can proceed if the individual supported donation.

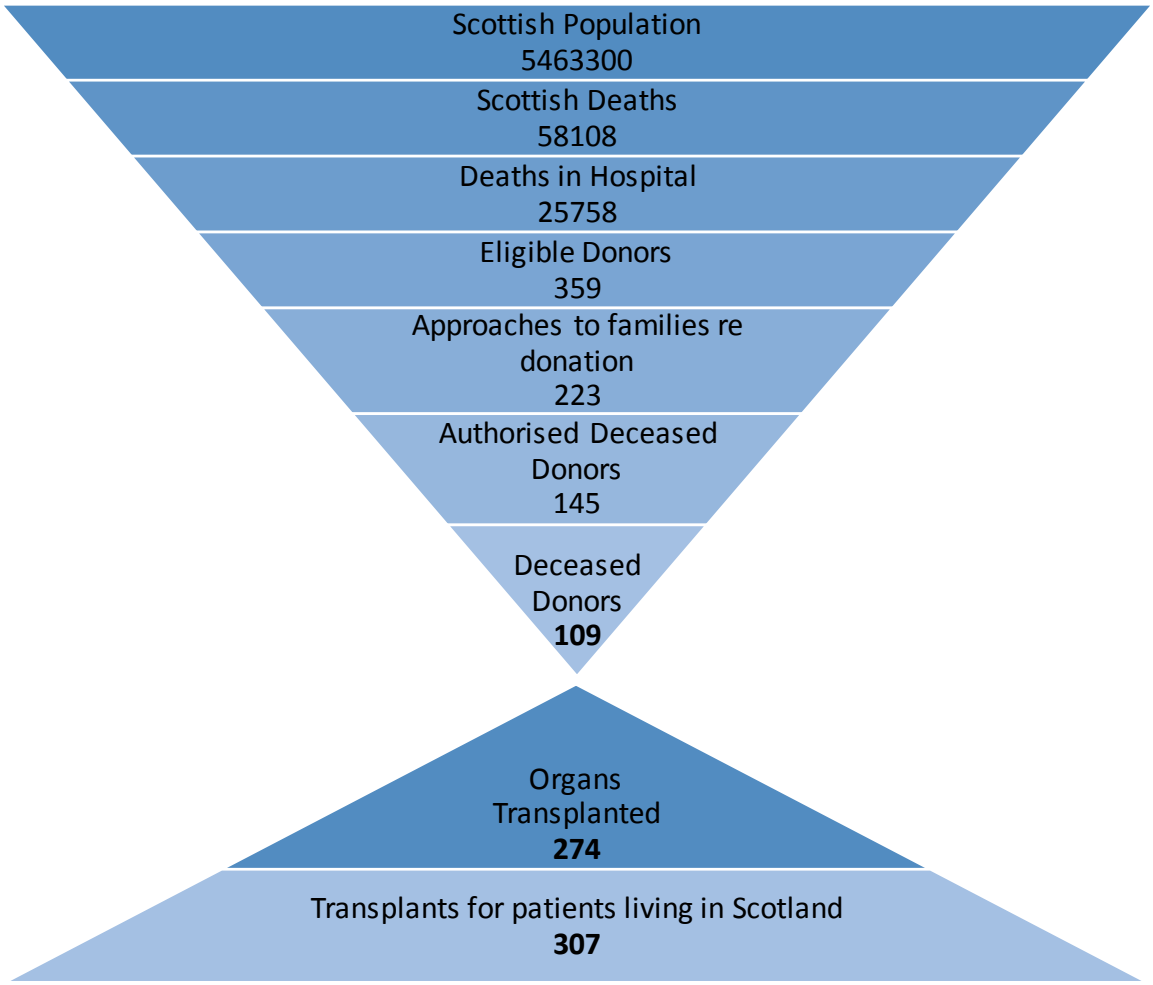
Previously all Specialist Nurses for Organ Donation (SNODs) in Scotland would approach families about the potential of donation, together with hospital staff, as well as taking forward all other parts of the donation process where donation is authorised. It is important to ensure Specialist Requesters (SR) or SNODs are involved in approaches to families as authorisation is much less likely to be given if a SNOD is not involved in the approach. For example, in 2019-20, organ donation was authorised in 71.4% of cases where a SNOD or SR was involved, but in 0% of the cases where no SNOD or SR was present. Using the SR model, a small group of six Specialist Requesters in Scotland will consistently be responsible for leading discussions with family members about donation. These discussions are very sensitive and challenging as they happen at a time when family members have only recently discovered that their relative has died or is about to die. SNODs will still be involved, but will usually take over from the Specialist Requester at the point where it is clear that donation has been authorised.

We will also monitor progress in reducing the number of cases where family members refuse to allow donation to proceed even though their loved one had opted in to donate via the ODR to establish whether Specialist Requesters help reduce these cases by encouraging families to support their family member's decision.

NHSBT is trialling the Specialist Requester model in partnership with the Scottish Government for three years. After the initial three year period, progress will be evaluated

to assess the effectiveness of using Specialist Requesters in increasing authorisation rates in Scotland. In a number of regions of England, evidence suggests that using Specialist Requesters, particularly where those requesters are experienced and approach families regularly, does increase authorisation rates. If authorisation rates have not increased, further work will be carried out with NHSBT and SDTG to consider what more can be learned from other nations or regions on improving authorisation rates.

Deceased Solid Organ Donors in Scotland – 2019-20



Data from National Records of Scotland, Public Health Scotland and NHSBT. Note – organs transplanted data is based on numbers of transplants from organs donated in Scottish hospitals.

Tissue and Eye Donation

3.2 Both through the introduction of opt out and on a continuing basis, we will support SNBTS to reduce missed opportunities for tissue donation by increasing NHS staff awareness across hospitals and hospices by raising awareness and reminding NHS staff of the importance of considering the potential of tissue donation for all deaths. There will be work carried out with hospitals, hospices and Organ Donation Committees to embed referral of potential tissue donors as part of standard end of life care. Staff in key hospitals will be issued with Tissue Donation cards to attach to a lanyard to help remind them when and how potential donors can be referred. We plan to monitor tissue referral rates and reasons for tissue donation not being authorised to try to consider if there are any further steps which should be taken to increase donation.

In 2019-20, 36% of families approached about tissue donation were not willing to speak to a tissue donor coordinator (TDC); work will therefore be progressed, particularly through the implementation of deemed authorisation, to look at whether there are ways to reduce the proportion of families who decline to discuss donation. The great majority of the families who do agree to speak to a TDC are content for donation to proceed.

Unfortunately eye donation in Scotland has declined in recent years, although there has been no significant decline in demand for cornea transplants. For example, in 2019/20 there were 281 cornea transplants carried out on patients living in Scotland, but only 46 donors in Scotland donated their eyes in that year. We believe that part of the shortfall is due to a lack of suitably trained retrieval staff being available to carry out the retrieval within 24 hours of the patient's death. It is important to ensure a robust eye retrieval service is in place and will work with SNBTS and NHSBT to monitor progress with the aim of ultimately ensuring that there are enough eye donors in Scotland to meet the demand for cornea transplants for patients in Scotland. In addition, to support this work, we aim to work with NHSBT to improve the data available on referrals and the reason why eye donation does not proceed following a referral.

Having better data will help identify key areas for improvement. We will therefore consider further how best to optimise levels of eye donation in Scotland and continue to promote public awareness about the importance of eye donation. While it is likely that reducing missed referrals and improvements in the retrieval service should increase eye donation in Scotland, SNBTS will work with a number of hospices to enable some of those who die out of hospital also to have the opportunity to donate their eyes.

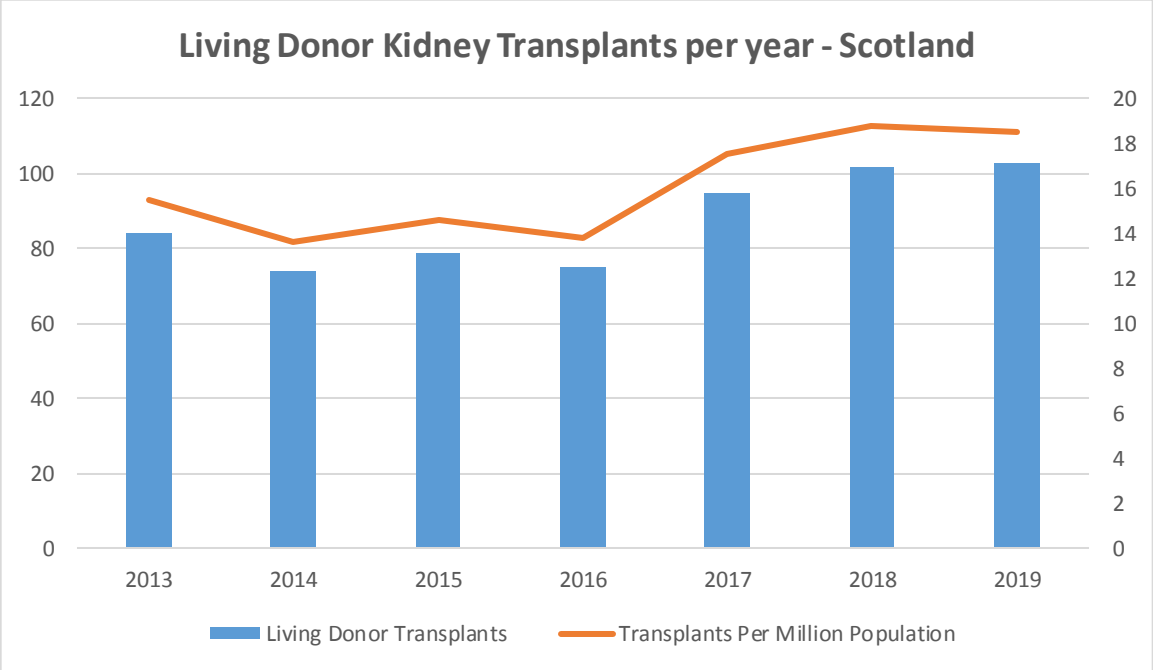
Key Recommendations		Short term 1 – 2 years Medium term 3 – 5 years	Lead
1	Ensure use of Specialist Requesters to approach families about organ donation in all donating hospitals to help improve authorisation and reduce overrides where the patient was on the ODR.	Short term – implementation already started	NHSBT
2	Monitor and review use of Specialist Requester model	Medium term	NHSBT and Scottish Government
3	Via opt out implementation and longer term, increase awareness raising among NHS staff about referring potential tissue donors.	Short to medium term (likely to be ongoing)	SNBTS and Scottish Government
4	Ensure a robust eye retrieval service for Scotland is in place and continue to monitor and review progress on increasing eye donation.	Short term - for the retrieval service Medium term - for monitoring and reviewing progress in increasing donation	SNBTS and NHSBT

Priority Four – Increasing Living Donation and Reducing the Wait for a Kidney Transplant

Any individual in Scotland who would benefit from kidney transplantation should ideally have no or minimal time on dialysis. Ensuring early assessment for kidney transplantation will facilitate consideration for both deceased and living donor transplant and allows timely access to transplantation. While it will not be feasible for everyone, we want to encourage all those who need a kidney transplant to consider and explore options for a living donor transplant as their first transplant.

A living donor kidney transplant offers the best long-term graft and patient survival, with on average 89% of recipients of a living donor transplant still alive after ten years post-transplant, compared to about 76-78% of patients who received a deceased donor transplant[5].

Chart 7



A Living Donor First Default and Transplant Decision Recording

4.1 It is important to make sure that all patients who may benefit from a kidney transplant are supported in exploring all options for a living donor transplant to improve their equity of access and achieve the best treatment outcome for them. As a result, Renal Units will be asked to **make a living donor transplant the 'default' option for a first transplant** for all patients (both adults and children) needing a kidney transplant so it can become the norm. We need to respect that some patients will not have anyone either willing or healthy enough to donate a kidney or they may feel strongly that they do not want their relatives or friends to put themselves at any risk by donating a kidney; it is

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

of course vitally important that no one feels in any way pressured into becoming a living donor. However, it is legitimate that living donation should be the first option to be explored and encouraged before considering a deceased donor transplant.

Work is already underway to ensure all patients in Scotland approaching end-stage renal failure (the point at which they may either need a transplant or need to go on dialysis) have a documented decision about whether they are suitable for and want to proceed with a living and/or deceased donor transplant. They should also have had a referral for a treatment options education session. Data on this should be recorded and collected in comparable formats throughout Scotland. We will continue to work with Renal Units via the Living Donation Scotland Board to implement this and will monitor if this work is effective in increasing access to living donor transplants for those who typically so far have been less likely to receive one, such as patients in lower income groups and those from minority ethnic communities.

Education and Choices

4.2 We will also continue to provide high quality, accessible information to patients and their families about living kidney donation and other treatment alternatives. The living donation information packs and resources on the Organ Donation Scotland website have been well used by patients and Renal Unit staff. An information pack has also been distributed to General Practitioners to increase their awareness about living kidney donation options. Work is underway to develop an online living donor transplantation education resource for renal and transplant staff throughout Scotland, using the TURAS platform.

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 we will seek to roll it out across Scotland to support and encourage open discussion within families and with close friends about choices.

Work has already begun to improve awareness of living kidney donation across the general population through publicity to increase understanding about both directed and non-directed (altruistic) donation. This work will continue into the new Action Plan period.

Providing guidance for NHS Boards on resourcing for Renal Units

4.3 To support the ambitions set out above, we recognise that increasing living donation will require Renal Units to undertake extra work, particularly to ‘work up’ potential living donors before they go to the relevant transplant unit, as well as to support the increasing numbers of patients who have received a transplant. While increasing living donation should over time help reduce the number of patients on dialysis and so the resources needed to support dialysis patients, the workload for units may still increase, particularly in the short to medium term. Therefore, we propose to ask the Living Donation Scotland Board to work with referring Renal Units and Transplant Centres to produce guidance for NHS Boards on recommended staffing levels to support living donation for differing levels of patient populations.

Improving access to kidney and liver transplantation

4.4 Work will continue to encourage all patients who have a relative or friend willing and healthy enough to donate them a kidney to use the UK Living Kidney Sharing Scheme (LKSS). This scheme allows patients to receive a living donor transplant if their donor is not a direct match for them. Even where the patient and their donor are a fairly good match, using the LKSS may provide the patient with a better long term outcome. This may be in the form of a better match or reduced sensitisation. Using the LKSS and involving altruistic donors in the chain of kidney 'swaps' can also provide the opportunity of a living donor transplant to patients on the deceased donor transplant waiting list who do not have their own living donor.

In addition, in line with the UK Strategy, we will support the Edinburgh Transplant Unit to increase awareness of living liver donation among patients. While this will not be appropriate for the majority of patients, where patients have someone willing and healthy enough to donate part of their liver, this may help enable those patients to access a transplant more quickly and so could help to reduce numbers of deaths on the waiting list.

	Key Recommendations	Short term 1 – 2 years Medium term 3 – 5 years	Lead
1	Ask Renal Units to make the default option for a first transplant for all patients needing a kidney transplant a living donor transplant.	Medium term	Renal Units, with support from the Living Donation Scotland Board
2	Subject to positive evaluation of the NHS Lothian REACH trial, a community, nurse-led programme of home visits to or other direct engagement (such as video calls) with patients and their family should be encouraged throughout Scotland.	Medium term	Living Donation Scotland Board and Renal Units
3	The Living Donation Scotland Board will prepare guidance for referring Renal Units on recommended staffing levels to support living donation.	Short term	Living Donation Scotland Board

Priority Five – Transplant Recipient Support and Aftercare

Patients often continue to need significant physical and mental health support after they have been discharged from hospital post-transplant. It is important to ensure services are as joined up as possible to enable patients to receive any follow-up care they need and, where possible, to receive this closer to home.

5.1 Work will be taken forward with transplant units and their patients to consider whether existing aftercare services need to be improved for recipients of some or all organs to ensure appropriate support across Scotland. Transplant units provide a range of physical and psychological support to patients before and shortly after their transplant, along with check-ups where needed and emergency support for patients experiencing very severe health problems as a result of their transplant. We will consider with transplant units how they can continue to ensure good communication with and advice and support is provided consistently to patients both pre- and post-transplant, both directly, but also by ensuring patients are aware of other organisations, such as peer-support groups and charities who can help. However, transplant units cannot provide all the healthcare a patient may need over the longer term after their transplant and patients normally need to access most follow-up support relating to side effects or complications, as well as any mental health support they need, via their local NHS Board.

This more local care can reduce the need for patient travel and avoids overloading transplant unit staff unnecessarily, but we need to make sure the relevant staff in NHS Boards' specialist teams and GPs have the right information and support to be able in turn to support transplant recipients. We know from feedback that some patients have raised concerns that communication and joint working between transplant units, NHS Boards' referring clinicians and GPs is not always ideal and this can sometimes lead to delays or confusion for patients. While Renal Units will already have a lot of experience of supporting patients who have had a kidney transplant, for other organs some medical staff in NHS Boards may have less experience of supporting recipients and of the types of side effects or complications they may suffer.

As a result, we plan to work with transplant units and NHS Boards to encourage and support transplant units to develop an improved, more patient-centred 'hub and spoke' model of care to provide better continuity of care for patients. We want to encourage NHS Boards to nominate transplant champions in their Board area. The hub and spoke approach may include offering telemedicine appointments or online advice to support patients to avoid them needing to travel (the lessons learned on this from the coronavirus pandemic can hopefully be transferred to longer term practice). It could also include providing more advice by phone to NHS Board medical staff on appropriate treatment for patients in cases where a patient's local Board feels they cannot support a patient appropriately without advice from their transplant unit. Over time, this should also help increase expertise within Boards and help ensure patients receive joined up and consistent support. Technology, such as apps, may in future also offer other potential means of helping monitor patients' health remotely and ensuring they are appropriately supported.

We also propose to review with the units whether more online guidance should be available to general practitioners or relevant hospital staff to increase awareness and expertise in caring for patients who have had particular transplants (particularly less common ones). Linked to the aims of priority seven on health improvement, we will consider whether this additional guidance should also include aspects such as diet and physical activity to help support transplant patients to keep their donated organ(s) in good condition; patients already receive some guidance on this, but additional ongoing support and advice may be helpful.

Many recipients also need psychological, counselling or other mental health support for a range of reasons, such as due to worry about how long the organ will last, the side effects of immunosuppressant medication or anxieties linked to survivor guilt and thinking about their donor and their family. While support is already provided by transplant units in the period pre- and shortly after the transplant, as part of our Mental Health Strategy[6], the Scottish Government is committed to continuing to increase the availability of and reducing waiting times for general mental health support from NHS Boards for both adults and children. Although COVID-19 has increased demands on mental health services, we will continue to work with NHS Boards to improve access. This will include making online support available for those patients for whom it is appropriate, which should help reduce waiting times for those patients.

Finally, the Scottish Government will continue to work with NHS Boards to explore options for improving access to electronic records of patients from other NHS Boards. The Electronic Patient Record (EPR) is expected to be delivered as part of the National Digital Platform (NDP) as a key component of Scotland's Digital Health & Care Strategy[7]. This is likely to take a few years to roll out, but will ensure up to date digital information can be shared securely across NHS Boards.

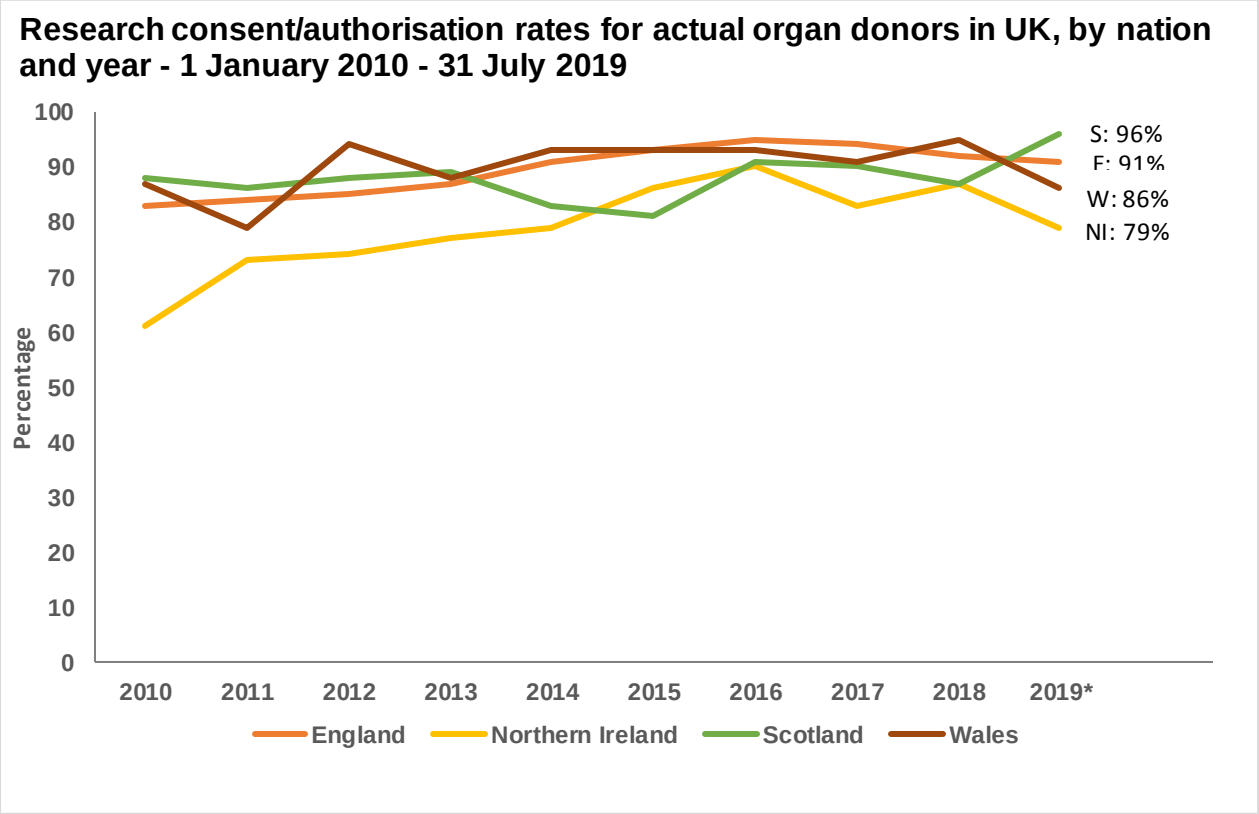
	Key Recommendations	Short term 1 – 2 years Medium term 3 – 5 years	Lead
1	Work to establish telemedicine and online support for those patients who need it to supplement local NHS Board support.	Short to medium term	Scottish Government and Transplant Units
2	Ensure NHS Board staff know where to access advice from transplant unit staff and can access expert advice within a reasonable timescale.	Short term	Transplant Units
3	Where appropriate, provide additional guidance to NHS Boards/GPs to help build their expertise on and ability to support patients locally post-transplant.	Short to medium term	Transplant Units, with support from the Scottish Government

[6] See https://www.gov.scot/publications/mental-health-strategy-2017-2027/
[7] See https://www.gov.scot/publications/scotlands-digital-health-care-strategy-enabling-connecting-empowering/

Priority Six – Research and Innovation

Alongside rolling out the use of novel technologies where there is evidence of their effectiveness, it is important to continue to support research in relation to organ and tissue transplantation and regenerative medicine. Research has the potential both to improve the effectiveness of transplanted organs and/or tissue, making them last longer or perform better for recipients, with fewer side effects.

Chart 8



*For donation year 2019, the data was collected from 01/01/19 to 31/07/19

6.1 Where a donor has agreed to donate their organs or tissue for transplantation it may often not be possible to use some, or even sometimes any, of their organs or tissue for transplantation. Particularly in cases where organs or tissue have been retrieved, it can be very disappointing for loved ones if the organs or tissue are found not to be safe to transplant. However, enabling them to be used for research instead can give some comfort that the person's organ(s) or tissues are still making a valuable contribution to potentially saving or improving patients' lives. The Scottish Government will support NHSBT, SNBTS and transplant units' work to promote the donation of organs and tissue for research, for example by raising awareness of the benefits of donating for research as well as for transplantation. Consistent with the aims of the UK Strategy, we will monitor rates of authorisation for research by nearest relatives, as well as the work of the Research, Innovation and Novel Technologies Advisory Group (RINTAG) in helping to improve the utilisation of organs and tissue for research where possible if they are not suitable for transplantation.

6.2 We will also continue to provide opportunities for transplant-related and regenerative medicine research to be carried out in Scotland, including for example research in areas such as immunosuppression, and will promote engagement with academic institutions and grant-funding bodies to support this. Scotland benefits from having a leading Centre for Regenerative Medicine in Edinburgh, which is at the forefront of research on advanced cellular therapeutics, along with other academic institutions carrying out regenerative medicine research. In the longer term, regenerative medicine has the potential to significantly improve the quality of transplanted organs and tissues, as well as potentially in future to provide alternative forms of treatment for certain conditions, which might possibly reduce the need for transplantation.

Key Recommendations		**Short term 1 – 2 years Medium term 3 – 5 years**	**Lead**
1	Increase public awareness about the benefits of donating organs or tissue for research.	Short to medium term	Scottish Government and NHSBT
2	Monitor progress and consider if further action is needed to increase donation and utilisation of organs or tissue for research.	Medium term	Scottish Government and NHSBT

Priority Seven – Public Health Improvement

While many people need transplants due to long-term medical conditions that could not be prevented, some develop organ failure due to factors which could have been avoided through a healthier lifestyle. For example, poor diet, a lack of physical activity, excessive alcohol consumption, smoking or drug use may all cause or contribute to different types of organ failure, such as liver, heart or kidney failure. Improving public health across Scotland should in the longer term both reduce the need for organ transplants, as well as reducing the incidence of other severe health conditions.

7.1 Although a key focus of this plan needs to be on increasing the number of transplants available for patients in Scotland, it is clear that based on current numbers of potential donors as well as on the increasing need for transplants, at least for some organs such as kidneys, actions to increase living and deceased donor numbers and organ utilisation will not be enough on their own to allow organ supply to meet the current demand.

Scotland is already embarking on a process of public health reform with a key aim of improving public health across Scotland. A new public health body, Public Health Scotland, has been established to improve collaboration between the health service, local authorities, the third sector and other key stakeholders to promote healthier lifestyles and help tackle the main preventable causes of ill health. The reform process has identified six public health priorities[8] which include priorities on: diet and physical activity; and the use of and harm from alcohol, tobacco and other drugs. Public Health Scotland will have a key role in supporting the delivery of the public health priorities, and so, as part of their long-term work, we will work with them to reduce the need for transplants, in the case of patients whose need for transplantation could be prevented.

We welcome the fact that the public health priorities are focused on health inequalities and aim to make sure that particular groups at higher risk or those who have so far been harder to reach with traditional messaging about health improvement are appropriately targeted. For example, we know that individuals from Asian communities are statistically more likely to develop conditions such as kidney failure and type 2 diabetes. Through the Peer Educator project with Kidney Research UK, there has already been considerable raising awareness of kidney disease amongst South Asian communities in Glasgow and Edinburgh. Work will continue to look at how best to improve awareness and encourage people in these communities to take action to avoid ill health.

The current reform of public health provides an important opportunity for public bodies and charities involved in public health to better align our collective efforts. We want to improve the health and wellbeing of the population by tackling poverty and reducing wider inequalities and the Public Health Priorities for Scotland, agreed with CoSLA, provide a focus for our national and local partners to work more effectively in partnership on key issues.

[8] See https://www.gov.scot/publications/scotlands-public-health-priorities/

7.2 Alongside this, early diagnosis of patients with symptoms of organ damage or failure may allow patients to take positive action to improve their health, which could in some cases reduce their risk of their organ function deteriorating further and leading to them needing a transplant in the future. While medical professionals across Scotland already aim to identify organ damage at an early stage, work will continue to explore any practical actions to improve this further. As part of priority five on improving support for transplant recipients, transplant units and NHS Boards should also continue to support and encourage patients to follow the guidance they are given on diet, activity and any other advice to ensure their donated organ continues to function as effectively as possible and keep themselves healthy.

Key Recommendations		Short term 1 – 2 years Medium term 3 – 5 years Long term 6 – 10 years	Lead
1	Work with Public Health Scotland to ensure its work to improve public health can help us to reduce organ failure across Scotland.	Long term – likely to go beyond this current plan.	Public Health Scotland, with support from the Scottish Government
2	The Scottish Government will also ensure its prevention policies on diet and healthy weight, physical activity, and alcohol, tobacco and drugs focus on health inequalities to help reduce organ failure across Scotland.	Long term – most of the measures contained in the five public health action plans published in 2018, and already being implemented, will have a long-term effect.	Scottish Government

Proposed Timeline

Short Term 2021 – 2022
Raise awareness across Scotland about the change in legislation, aiming to reach as many people as possible, including harder to reach groups. Regular awareness raising will continue following introduction of deemed authorisation.
Ensure key staff likely to be involved in approaching families about deceased donation receive training and guidance on the new legal requirements in relation to deemed authorisation and pre-death procedures - to be delivered by March 2021. Also put in place wider general awareness raising for other NHS staff.
Raise awareness among relevant staff across NHS Boards to seek to ensure all those patients who would be likely to benefit from a transplant are offered the opportunity.
Ensure use of Specialist Requesters to approach families about organ donation in all donating hospitals. Implementation has already started.
Ensure a robust eye retrieval service for Scotland is in place and continue to monitor and review progress on increasing eye donation.
The Living Donation Scotland Board will prepare guidance for referring Renal Units on recommended staffing levels to support living donation.
Ensure NHS Board staff know where to access advice from transplant unit staff and can access expert advice within a reasonable timescale.

Short to Medium Term 2021 – 2023
Keep the pre-death procedures regulations under review. If changes to either Type A or Type B regulations are proposed, ensure these proposals can be considered and, if appropriate, amendments can be made.
Work to ensure sustainable, patient-centred transplant services, including exploring options for increased shared services between Renal units, in particular to avoid the need for patients to miss out on any suitable organs offered for them.
Via opt out implementation and longer term, increase awareness raising among NHS staff about referring potential tissue donors.
Work to establish telemedicine support for those patients who need it to supplement local NHS Board support.
Where appropriate, provide additional guidance to NHS Boards/GPs to help build their expertise on and ability to support patients locally post-transplant.

Increase public awareness about the benefits of donating organs or tissue for research.

Medium Term 2023 – 2025
Undertake an evaluation of the deemed authorisation system and seek to learn any lessons from the evaluation findings by late 2025.
Increase the number of viable organs for transplantation by using novel technologies, such as rolling out use of machine perfusion. Subject to the findings of initial feasibility work, consider moving ahead with development of a Scottish Assessment and Recovery Centre.
Monitor and review use of Specialist Requester model.
Ask Renal Units to make the default option for a first transplant for all patients needing a kidney transplant a living donor transplant.
Continue to monitor and review progress on increasing eye donation.
Subject to positive evaluation of the NHS Lothian REACH trial, a community, nurse-led programme of home visits to or other direct engagement with patients and their family should be encouraged throughout Scotland.
Monitor progress and consider if further action is needed to increase donation and utilisation of organs or tissue for research.

Longer Term 2026 - 2030
Work with Public Health Scotland to ensure its work to improve public health can help us to reduce organ failure across Scotland.
The Scottish Government will also ensure its prevention policies on diet and healthy weight, physical activity, and alcohol, tobacco and drugs focus on health inequalities to help reduce organ failure across Scotland.

This publication is available at **www.gov.scot**

Any enquiries regarding this publication should be sent to us at

The Scottish Government
St Andrew's House
Edinburgh
EH1 3DG

ISBN: 978-1-80004-664-1 (web only)

Published by The Scottish Government, March 2021

Produced for The Scottish Government by APS Group Scotland, 21 Tennant Street, Edinburgh EH6 5NA
PPDAS830066 (03/21)