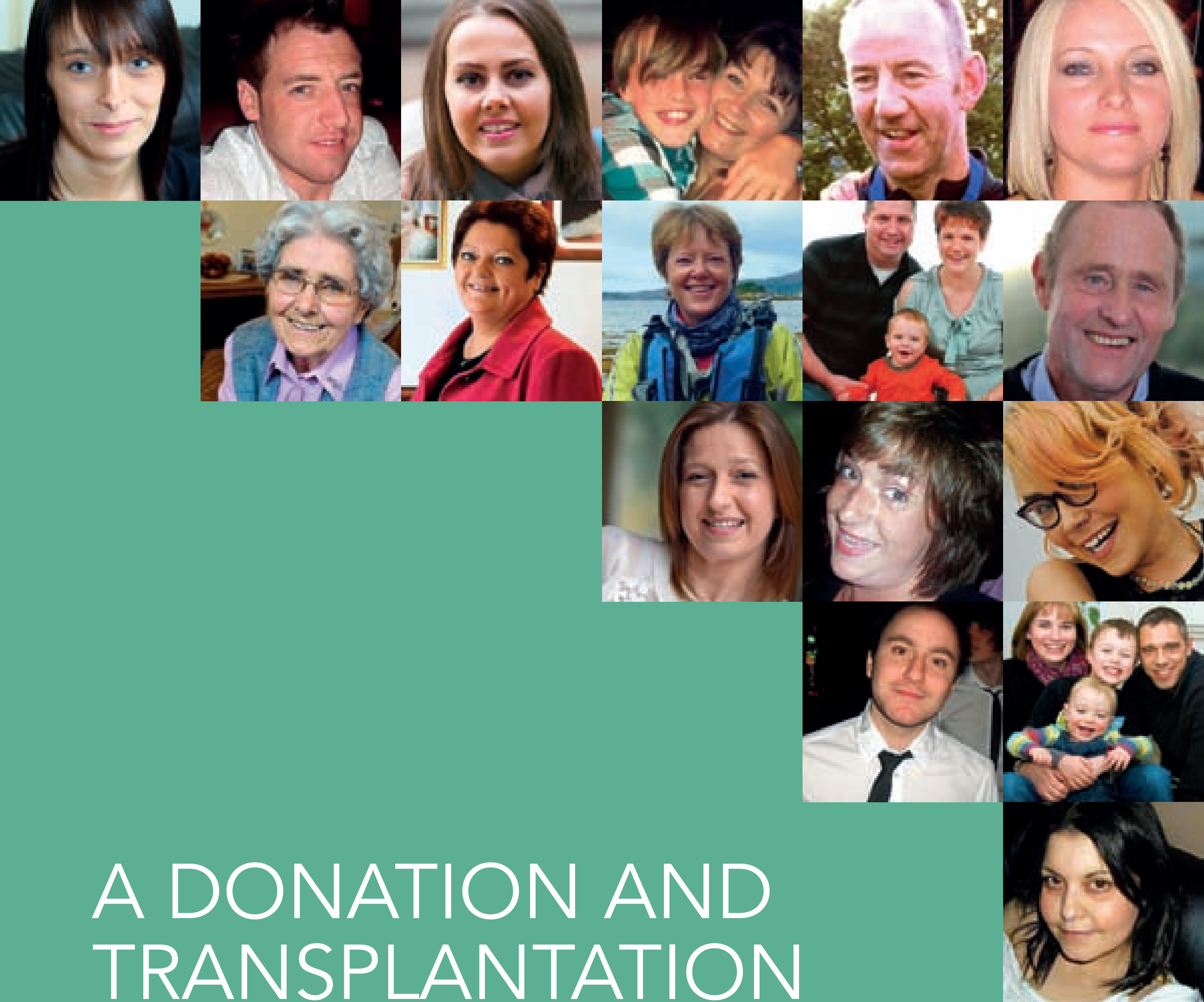

A DONATION AND TRANSPLANTATION PLAN FOR SCOTLAND 2013-2020

More donors, more transplants, more lives saved

The Scottish Government
Riaghaltas na h-Alba

A DONATION AND TRANSPLANTATION PLAN FOR SCOTLAND 2013-2020

More donors, more transplants, more lives saved

The Scottish Government, Edinburgh 2013

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MINISTERIAL FOREWORD

It is my pleasure to provide a foreword to the Scottish Government‟s new Donation and Transplantation Plan.

Organ and tissue donation is a unique act of benevolence. Many donations occur immediately following tragic events or at a time of great sorrow. This proximity to loss and grief only makes the willingness of families to think of other people and to donate their loved ones‟ organs all the more special. The decision may be taken instinctively at the time, but I know that, later on, comfort can come from the knowledge that such a loss has benefited others. And no less significant is the gift given by living donors, who are willing to donate an organ solely because it can save or improve someone else‟s life.

This plan sets out the ways in which we hope to improve donation and transplantation in Scotland. The plan builds on the very good progress we have made under the auspices of the Organ Donation Taskforce over the last five years. Scotland has achieved a 74% increase in donations over the last five-year period, as well as a 36% increase in transplants with deceased donor organs. But we know we can do better, and this plan seeks to address those areas where there is room for improvement, or where we want to do something different or something new.

The donation and transplantation of organs operates on a co-ordinated and collaborative basis across the United Kingdom. It is in the best interests of patients to ensure the best match between donor and recipients, and this can be best achieved by matching organs to the largest group of patients. Our approach is similar to that undertaken in many other parts of the world, including in a number of multi-country European transplant collaborations. This means we will work closely with the other parts of the UK and with NHS Blood and Transplant, the organisation which manages the NHS organ donor register and the allocation of organs, amongst other things. The four UK countries have developed an over-arching Strategy for organ donation and transplantation, and this Scottish plan is a companion to that, adding particular domestic focus for the Scottish context.

It will be clear when you read this plan how complex and multi-faceted the whole issue of organ donation and transplantation is. No single thing will revolutionise donation rates in this country – we know this to be true from experience elsewhere in the world. Rather we need to tackle every single weak link in the chain, and we need to drive continuous improvement. This plan seeks to do just that. It sets out twenty-one recommendations right across the pathway, from ensuring that everybody has the opportunity to make their wishes known, whatever those wishes may be, to ensuring that those who receive transplants have the appropriate after-care and follow-up. The Plan commits us to meet certain targets by 2020. We want to have amongst the best organ donation and transplantation rates in the world. These are testing ambitions, but they are achievable.

Ultimately, however, we need to keep in mind clearly the reason for all of this activity. We need to treat every donation as the valuable gift it is. Every donor and every donor family deserves our thanks and recognition, and it is our responsibility to ensure that every donation counts. And we need to think about the very many lives saved and improved because of somebody else‟s generosity. The NHS is a facilitator in this event – it is there to help the donor fulfil their wish to give the gift of life. It reflects the very best of humanity and society, and the NHS – indeed, society as a whole – has a duty to do all it can to support the wishes of donors.

I would like to dedicate this plan to every donor who has given that gift, and to all those people who have made it known that in the event of their death they would like to help somebody else to live.

Every photograph on the front cover of this publication depicts someone in Scotland whose life has been improved by receiving a transplant. These people, and many more like them, have been touched by the gift given by another. I look forward to seeing the very real progress we will make over the coming years, so that many more people can benefit from such a gift, and many more lives are saved and improved.

Michael Matheson MSP
Minister for Public Health

INTRODUCTION AND BACKGROUND

Where we are

1.1 The transplantation of organs is one of medicine‟s great success stories. Conditions that severely limit lives, or which are ultimately fatal, can now be cured or significantly improved by the transplantation of replacement organs from deceased and living donors. These procedures save and improve lives beyond measure. Yet despite the very real benefits of transplantation – both for the individual concerned and for the NHS as a whole – there are still too few organs available, and too few transplants carried out. Patients continue to die while waiting for the transplant which could transform their lives.

1.2 It has been recognised for some time that Scotland – and the UK more generally – compares poorly in terms of deceased donation rates with other countries in Europe. In order to address this, a UK Organ Donation Taskforce (ODTF) was established in 2006 to look at the obstacles to organ donation and to suggest solutions which would deliver an increase in transplants. The ODTF published its report in 2008, making 14 recommendations which it believed could lead to a 50% increase in organ donation within five years.

1.3 Like the other UK countries, Scotland has worked hard to deliver the ODTF recommendations and significant progress has been made:

- 2012/13 saw the highest ever number (94) of deceased organ donors in Scotland – an increase of 74% from since 2007/08.
- Scotland now has the UK‟s highest percentage of residents signed up to the NHS Organ Donor Register – over 41% of the population had joined the register at the end of 2012/13, compared to the UK average of 31%.
- 2012/13 saw the highest ever number (285) of transplant operations from deceased donors undertaken on Scottish recipients – an increase of almost 36% from around 210 operations in 2007/08.

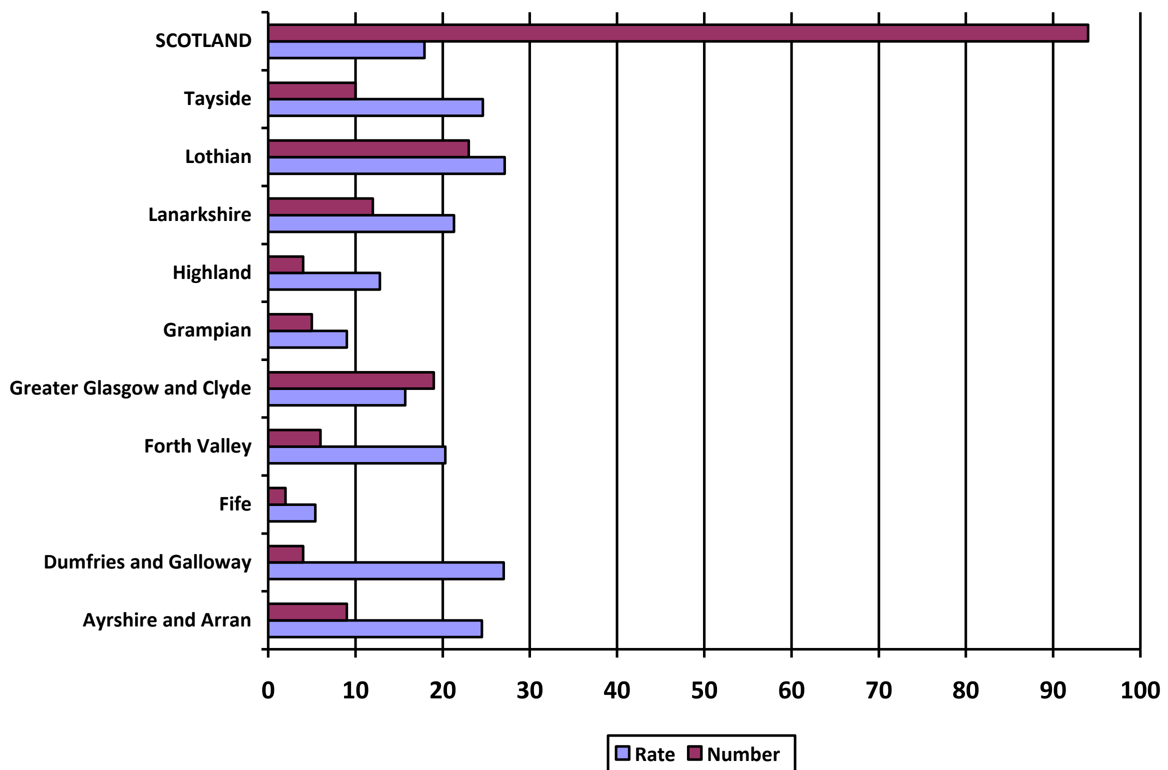
Full details of Scotland‟s progress against the ODTF recommendations are set out in **Annex B**.

1.4 Despite these achievements, there are still many areas where further work is needed, and improvements can be made. For example:

- We know that many people who are supportive of organ donation have not yet signed up to the NHS Organ Donor Register. Enabling and encouraging those people to sign up to the Register and to make their loved ones aware of their wishes is a key priority. A survey undertaken in early 2012 by the Scottish Government demonstrated that only 5% of the population oppose organ donation in principle.
- We know there are circumstances where opportunities for donation are missed due to failures by the NHS to refer potential donors to Specialist Nurses in Organ Donation. This is true even in circumstances where the deceased has a recorded wish to donate (for example, by being on the Register, carrying a donor card or by telling their loved ones of their wishes).

- We know that in some cases, the families of individuals who have expressed a wish to donate do not receive timely information or support from the specialist staff trained in the donation process.
- We know that there is a wide variation in donation rates across the NHS in Scotland. While some variation should be expected with small numbers, this may not fully explain the extent of variation seen (see chart 1 below).

Chart 1: Organ donation numbers and rates per million population (pmp) in Scottish NHS Boards 2012/13



Note: NHS Boards with no donors in 2012/13 are not shown.

1.5 We want Scotland to be amongst the best performing countries in the world for donation and transplantation. This plan sets out the priority areas of work that need to be tackled over the period to 2020 to enable us to reach this goal. If the following recommendations are implemented, we believe that by 2020, donation, transplantation and family refusal rates in Scotland should be on par with the best performing countries in the world.

By 2020, in Scotland:

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

The Scottish Transplant Group

1.6 The Scottish Transplant Group (STG) was established in 2001 on the back of the Acute Services Review and was tasked with developing the first *Organ Donation Strategy for Scotland* (published June 2002[1]). Since that time the STG has continued to meet quarterly and provides advice to Scottish Ministers on all issues relating to organ donation, transplantation and tissue donation including implementation of the ODTF Recommendations.

1.7 As the key body providing advice to Ministers, the STG was asked to develop a plan to follow the ODTF Recommendations. The Group has had a key role in identifying the priorities for action, and in shaping these into a series of meaningful recommendations. In their work, the STG has had cognisance of the work being undertaken at a UK level on the UK-wide Strategy (see paragraph 1.14 below).

1.8 The STG will have an ongoing role under this new plan. The Group will be expected to monitor progress against the recommendations made – both in this plan and in the UK-wide Strategy – and report to Ministers on an annual basis.

The UK and European context

1.9 Organ donation and transplantation has always been delivered on a collaborative basis across the UK. It is in the best interests of patients to ensure that organs have the best match to recipients as this maximises the potential for good clinical outcomes and reduces the risk of graft failure or the need for re-transplantation. Ensuring the closest match between organ and recipient can be best achieved by sharing organs and expertise across the UK. This approach also means that patients in Scotland have access to rare or specialised procedures that are not available in Scotland.

1.10 Although the constitution of the UK may change in the coming years in light of the referendum on Scottish independence, organ donation and transplantation should continue to work on a collaborative basis to ensure the best outcomes for all patients in all parts of the country. This mirrors the experience in other parts of Europe where groups of countries work collaboratively to achieve the best outcomes for their patients. (For example, Scandiatransplant and Eurotransplant.) This plan is predicated on the basis that – whatever the constitutional developments – the existing collaborative approach will continue.

1.11 Organ donation and transplantation activity across the UK is co-ordinated by NHS Blood and Transplant, an England and Wales Special Health Authority which operates in Scotland under a contractual arrangement with the Scottish Government. NHSBT manages certain necessary activities such as the UK-wide NHS Organ Donor Register; the allocation of organs across the UK; management of data and information; and the training and management of specialist nurses and clinical leads. Scotland will continue to engage with NHSBT and the other UK Health Departments to ensure patients in Scotland have the best clinical outcomes. The nature of that

[1] An Organ Donation Strategy for Scotland, Scottish Transplant Group, 2002: http://www.sehd.scot.nhs.uk/publications/odss/odss-00.htm

relationship may change in light of the changing constitutional situation, or for other reasons, but the need for collaboration will not reduce.

1.12 Organ donation and transplantation also operates within a robust European and domestic regulatory framework. For Scotland, as with the rest of the UK, the Human Tissue Authority (HTA) is the regulatory body. The Scottish Transplant Group and donation and transplant services in Scotland work closely with the HTA to ensure services meet the necessary regulatory standards.

1.13 Tissue donation in Scotland is managed by the Scottish National Blood Transfusion Service (SNBTS). This has resulted in close collaboration between organ and tissue donation which in turn has resulted in common education programmes, documentation and sharing of organs, i.e. hearts which cannot be placed are retrieved and valves are retrieved from them.

The NHSBT Strategy

1.14 The development of a new UK-wide Strategy on organ donation and transplantation has been co-ordinated by NHSBT on behalf of the four UK Health Departments. The UK Strategy is available on the NHSBT website at www.nhsbt.nhs.uk/to2020. This Strategy is the first document since the report of the UK Organ Donation Task Force to set out the key areas where further activity is required across the UK as a whole.

1.15 This Scottish plan is very much in line with, and intended to complement, the UK Strategy document. Where the UK document sets out general principles and considers those elements of organ donation and transplantation which are managed or can best be addressed across the UK as a whole, the Scottish plan focuses specifically on the devolved health infrastructure in Scotland and those activities which may be unique to Scotland, or delivered differently. The two documents are inter-related and inter-dependent.

FIVE PRIORITIES FOR ORGAN DONATION AND TRANSPLANTATION IN SCOTLAND

2.1 The successful delivery of organ donation and transplantation is a complex and multi-faceted issue. Achieving high donation rates, successful transplants and good patient outcomes depends on the intricate machinery of the NHS operating responsively, quickly and effectively. When this machinery works imperfectly, opportunities for donation and transplantation can be lost.

2.2 Equally complex are the moral, ethical and legal issues which surround donation and transplantation. The widespread public and professional support for organ donation depends upon the active consideration of some of these difficult and sensitive issues. Everybody in Scotland – public or professional – should be able to access the information they need to take a considered view on these issues. Where an individual has decided that they wish to donate their organs after death then it is the responsibility the NHS in Scotland to do all that it can to fulfil such wishes. Where an individual does not wish to donate then it is imperative that these wishes are respected.

2.3 This plan cannot address all of these issues. In order to make progress it is important that we focus our energies on the most important weaknesses and target our resources at the service or infrastructure changes which will have the biggest benefit.

2.4 On this basis the Scottish Transplant Group was asked to identify priorities for action over the period to 2020. Based on their own considerations, and informed by the NHSBT UK Strategy, the STG has identified the following five high-level priorities for action in Scotland:

- Priority 1: We should continue to increase the number of people in Scotland who have made their wishes about donation known;
- Priority 2: We should increase the availability of organs for transplantation;
- Priority 3: We should make sure that every donation counts;
- Priority 4: We should ensure that all parts of NHSScotland are knowledgeable about and support donation and transplantation; and
- Priority 5: We should ensure that the public in Scotland is informed and engaged about organ donation and transplantation.

2.5 The following chapters consider each of these priorities in turn and set out the key activities we will take forward over the next seven years to make progress. If we are successful we are confident that we will be able to replicate the experience of other parts of the world where donation rates have increased significantly as a result of a concerted effort by governments and health services.

PRIORITY 1: INCREASING THE NUMBER OF PEOPLE IN SCOTLAND WHO HAVE MADE THEIR WISHES ABOUT DONATION KNOWN

Introduction

3.1 In Scotland, the Human Tissue (Scotland) Act 2006 sets down the legal basis for organ, tissue and cellular donation and transplantation. Under the terms of the Act, individuals can authorise the use of their organs after death for the purposes of, amongst other things, transplantation. This authorisation can be in the form of a discussion with relatives or in writing (for example, by carrying a donor card), or by signing up to the NHS Organ Donor Register.

3.2 It is not necessary to be on the NHS Organ Donor Register to become a donor. Where any individual dies in circumstances that might allow for donation, regardless of whether or not they are on the NHS Organ Donor Register, the NHS should discuss with family members whether or not the deceased had made their wishes known. In circumstances where wishes had not been made known family members can still authorise donation on behalf of the deceased. It is of note that in Scotland over the last five years 62% of donors were **not** on the Register at the point of death.

3.3 The donation process should however work most efficiently and effectively when those who wish to donate have signed up to the NHS Organ Donor Register. We also know that families are more likely to authorise donation when an individual has expressed their wish to donate. For these reasons, it is important that we do all we can to enable everybody to make their decision known by registering.

Where are we?

3.4 Over the last five years the number and proportion of people in Scotland on the NHS Organ Donor Register has increased markedly – from 29% in 2007/08 to over 41% at the end of 2012/13. Amongst the UK countries, Scotland now has the highest proportion of its population on the Register.

3.5 A key driver of this increase has been the annual, national **awareness-raising campaigns** which the Scottish Government has funded. Evidence shows that in the months when the national campaign is running the numbers signing up to the register increase significantly – for example in November 2012, following the launch of the annual campaign in October 2012, there were 23,000 new registrations. The new Scottish organ donation website – http://www.organdonationscotland.org/ – supported this activity by allowing people to sign up to the Register on line, and on the site, without requiring a click through to a separate NHSBT website.

3.6 Scotland and the other UK countries currently operate an „opt-in‟ model of consent, where consent or authorisation is not assumed and donors (or their families) have to explicitly authorise donation. The Welsh Government is in the process of legislating to introduce an „opt-out‟ model of consent.

3.7 Since 2005 a national organ donation **schools pack**, possibly the first of its kind anywhere, has been made available to all secondary schools across Scotland. This pack, which also addresses tissue donation, was updated and re-launched in 2010 and a recent independent evaluation showed that 98% of teachers who have used the pack say it is relevant and engaging for students, while 88% of pupils recognised the importance of organ donation and would recommend its continued use in schools. The pack is now recognised internationally as an excellent resource and other countries and institutions such as Australia and the World Health Organization have shown an interest in adapting it.

Key actions

3.8 In order to continue increasing the proportion of the population on the NHS Organ Donor Register it is vital that we continue to raise awareness of organ donation, and encourage people to register. The Human Tissue (Scotland) Act 2006 places a legislative duty upon Scottish Ministers to promote and raise awareness of donation and transplantation. **The Scottish Government should continue to fund and deliver high profile organ donation awareness raising campaigns. (Recommendation 1a)** As part of this work the new Scottish organ donation website should be maintained and developed as necessary, to enable Scottish residents to have up-to-date information on organ donation and the ability to easily and simply join the Register. This action is consistent with recommendation 13 made by the ODTF:

> "There is an urgent requirement to identify and implement the most effective methods through which organ donation and the „gift of life" can be promoted to the general public, and specifically to the Black and Minority Ethnic population"

3.9 Although Scotland does not have a large black, Asian or minority ethnic (BAME) population (around 2% in 2001 census – although the 2011 census might show an increase on this) ethnic minorities are at greater risk of conditions that might lead to transplantation being required (diabetes, heart disease). It is for this reason that specific work has already been undertaken, including promotion of organ donation at cultural festivals such as Hungama and the Glasgow and Edinburgh Melas, at faith venues (gurdwaras, mandirs and mosques) and during religious celebrations (Eid and Vaisakhi). In recent years Scotland has also seen an increase in the number of residents from other parts of Europe such as Poland. Information and awareness-raising activities should also give consideration to the information needs of such populations. **The Scottish Government should ensure that proportionate targeted awareness raising and education work continues with BAME and other relevant communities in Scotland, linking up to similar work across the UK as appropriate. (Recommendation 1b)**

3.10 Members of the Scottish Transplant Group have previously provided views on the potential benefits of the introduction of an „opt-out" system of consent within Scotland. There is no consensus amongst members of the STG as to whether or not „opt-out" would increase donation rates in Scotland. Given this, and the fact that significant improvements have been achieved over the last five years in relation to donation and transplantation rates in Scotland, **the Scottish Government should await evaluation of the move to 'opt-out' in Wales before making any decision**

about the introduction of opt-out in Scotland. (Recommendation 2) In the meantime the Scottish Government, the Scottish Transplant Group, and other key partners should focus on delivering the recommendations within this plan.

3.11 The schools pack has been recognised internationally as a valuable tool to educate and inform children about organ donation and transplantation. **The Scottish Government should ensure that the schools pack continues to be maintained and updated as necessary, and consideration should be given to providing the pack in other accessible formats, such as in e-book format. (Recommendation 3)**

PRIORITY 2: INCREASING THE AVAILABILITY OF ORGANS

Introduction

4.1 The ultimate aim of this plan is to ensure that as many Scots as possible can receive the life-saving or life-changing transplants they need. The most significant limiting factor to the ability to undertake transplants is the availability of organs. The numbers of people who have expressed a wish to donate, or who have signed up to the NHS Organ Donor Register is only of value if the NHS has the right systems in place to ensure that organs can be donated by those who wish to in appropriate circumstances.

4.2 Currently, organs for transplantation can be made available in the following ways:

- Through **deceased donation**, or donation after death, specifically:
    - Donation after **brain stem death** (DBD), from individuals who generally have been pronounced dead in an Intensive Care Unit (ICU) using the neurological criteria known as 'brain stem death testing' using the *Code of Practice for the Diagnosis and Confirmation of Death* published in 2008 by the Academy of Medical Royal Colleges[2].
    - Donation after **circulatory death** (DCD), from individuals who generally die in critical care and emergency medicine areas as a result of heart or circulatory failure and who are pronounced dead following observation of cessation of heart and respiratory activity.
- Through **living donation**, in the case of kidneys or liver.

4.3 DBD was traditionally the main source for most transplanted organs, but in the last five years DCD donation has increased, and has, in fact, been the main driver for increasing donation rates across the UK, and in Scotland especially, although Scotland has so far maintained its rate of DBD donation unlike other parts of the UK. DCD donation gives rise to specific issues, not least the fact that hearts cannot currently be donated by DCD donors, however, that may change in the future. Living donation has also increased in recent years and is an important area for development.

4.4 A very recent development in Scotland relates to the pilot of **DCD Category II[3] donation** in NHS Lothian. This pilot commenced in early 2013 and seeks to enable those people who suffer a witnessed cardiac arrest, and who are already on

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[2] http://www.aomrc.org.uk/publications/statements/doc_view/42-a-code-of-practice-for-the-diagnosis-and-confirmation-of-death.html

[3] An international meeting on non-heart-beating (DCD) donation held in Maastricht in 1995 identified four categories of potential non-heart-beating organ donors. This list was subsequently amended to include a fifth category. The five categories can be split into those which can be described as uncontrolled, where donation cannot be planned (for example Category I, where someone is dead on arrival at hospital) or controlled, where donation can be planned and organ outcomes optimised (for example Category IV, cardiac arrest in a brainstem dead donor). The full list of Maastrict categories is available at: http://bja.oxfordjournals.org/content/95/5/592/T1.expansion.html

making their wishes known to their loved ones), to become donors in circumstances where all efforts to resuscitate and revive prove futile. Currently, individuals who die in such circumstances would not be able to donate organs. Such schemes operate in other parts of the world and the NHS Lothian pilot – currently the only one in the UK – is attempting to evaluate the potential impact of such an approach for Scotland. Tissue co-ordinators and specialist nurses for organ donation are working collaboratively on this pilot with mutual benefit to both tissue and organ donation.

4.5 For all forms of deceased donation, in order for donations to proceed, potential donors need to be referred to Specialist Nurses for Organ Donation (SNODs) in a timely way, either:

- for DBD, prior to testing, when the decision to test for death using neurological criteria is made and documented; or
- for DCD, when the decision that continuing treatment is not in the patient"s overall best interests is made and documented.

If referral to the SNODs does not happen in good time then the opportunity to donate can be lost.

4.6 Part of the role of the SNOD is to check the individual"s wishes (by checking the NHS Organ Donor Register) and to speak to the family. The SNOD has a key role in ensuring that the family or next-of-kin feel able to support donation where the deceased had made known a wish to donate, or can take an informed view in instances where the deceased had not made their wishes known. Even though the law in Scotland allows donation to proceed in the absence of family authorisation, in practice, donation would not currently proceed without this support. At all times SNODs are devoted to the care and ongoing support of the potential donor"s family, often many years into the future, providing families with regular updates, and including them in remembrance services.

4.7 The SNOD also has a key role in discussing with Procurators Fiscal the potential for donation in circumstances where a criminal prosecution or police investigation into the cause of death may be necessary. Procurators Fiscal (PF) can refuse to allow donation to proceed, or can apply conditions, such as that only abdominal organs may be donated. An agreement exists between the Scottish Transplant Group and COPFS/Scottish Fatalities Investigation Unit covering procedures around organ donation. This has recently been updated and plays a key role in fostering good relations and minimising the number of cases where a Fiscal refuses to allow donation to proceed.

Where are we?

4.8 Historically, Scotland and the UK have not compared well to the best performing countries in terms of rates of deceased donations. Significant progress has been made in recent years, however, and the picture has changed somewhat, specifically:

- The UK now achieves 19.1 donations per million population, and Scotland 17.9 (2012/13);

- This compares with the best performing countries, such as Spain (35.3 donors pmp) and Croatia (33.6 donors pmp);
- However, the UK and Scotland do perform very well in terms of DCD donation, with higher rates of this sort of donation than many other countries;
- The UK and Scotland also have some of the highest rates in the world of live donation.

4.9 We know that potential donors are missed as a result of a **lack of referral** to SNODs. The SNODs are responsible for instigating the NHS Organ Donor Register checks, the authorisation processes and for commencing a comprehensive assessment of the donor. From Scottish held data, we know that in 2012/13, a total of 10 likely brain dead patients and 20 patients having life-sustaining treatment withdrawn, who may have become donors, were neither notified nor referred to the SNOD service for assessment. Several of those patients had in life expressed a wish to donate. This is a failure of the NHS to support the wishes of the deceased. Each potential donor missed can equate to as many as seven transplant operations.

4.10 We know that good progress has been made in Scotland towards reducing the rate of **family refusals** to donation, particularly in the case of DBD donation, where family refusal rates are in line with the best performing countries at around 20-25%. Refusal rates are however higher in DCD donation cases, for a variety of reasons. We also know that family refusal rates are far lower when discussions with families about donation are planned, with both the SNOD and the referring clinician approaching the family together. SNODs have the ability to sit with families for several hours if necessary, providing detailed information and answering questions. The family refusal rate for tissue donation is high (circa 65%) and further work is required to understand the reasons behind this and the factors that may be tackled to reduce this figure.

4.11 PF refusal rates can vary from year to year, and that can be because PFs move posts relatively frequently and may only rarely have to take a view on potential donation, but a lot of work has been done recently to provide information and advice to PFs to minimise the number of refusals.

4.12 Rates of living donation in Scotland have been steady in recent years, with between 50 and 60 living kidney donors every year, and very small numbers of living liver donation. NHSBT recently published a UK-wide *Living Donation Strategy* which makes a number of recommendations relevant to Scotland.

Key actions

4.13 It is important that the rate of donation in Scotland continues to increase, and the Scottish Government would like donation rates in Scotland to reach those of the best performing countries. In order to achieve this, it is essential that all potential donors are referred to SNODs for assessment. Any failure to refer a potential donor to SNODs for assessment is unacceptable, and this is particularly true in the case of individuals who are already on the NHS Donor Register. **The Scottish Transplant Group should work with NHS Boards to develop tangible approaches to minimising and eliminating missed referrals, working in partnership with Scottish Government, NHSBT and others. (Recommendation 4a)**

4.14 **The Scottish Government should publish data on an annual basis detailing the number and type (DBD and DCD) of potential referrals that have been missed and in which NHS Board areas, to support NHS Boards in identifying and rectifying potential barriers to referral. Such data, which could also include tissue donation data should be published in the annual donation report card (see Recommendation 18 below). (Recommendation 4b)**

4.15 The other main limitation on the availability of organs is the rate of family refusals and the impact of PF refusals to donation. **NHS Boards and clinicians should ensure that all discussions with family members about the potential for donation involves a SNOD. The Scottish Transplant Group should monitor data on the rate of family refusals and report annually to Scottish Ministers. (Recommendation 5)**

4.16 **The Scottish Transplant Group should continue to work closely with the Crown Office and the Scottish Fatalities Investigation Unit (SFIU) to ensure that Fiscals have the information they need to make informed decisions about donation. Such work should involve annual training days involving the criminal justice and transplant communities. (Recommendation 6)**

4.17 The DCD Category II pilot in NHS Lothian is an important piece of work, and reflects the NHS in Scotland‟s desire to try new approaches to increase the number of donations that take place. **The Scottish Transplant Group and Scottish Government should continue to support the DCD category II pilot in Edinburgh. That pilot should be fully evaluated and lessons learned and disseminated across the UK. If the pilot is successful consideration should be given to operating similar schemes in other parts of Scotland – although such schemes may only be viable in Edinburgh and Glasgow, where there is rapid access to large emergency departments and a local organ retrieval team. (Recommendation 7)**

4.18 Living donation continues to be an important source of a significant number of kidneys. The Scottish Transplant Group should consider the NHSBT Living Donation Strategy and take forward recommendations as appropriate. **The Scottish Government should ask National Service Division of NSS to look at the potential risks and benefits of moving to national commissioning of kidney transplantation in Scotland**. **(Recommendation 8)**

4.19 In order to ensure that living donors are not disadvantaged as a result of their donation, Scottish guidance exists on reimbursement of expenses[4]. However, that guidance – in a letter from the Scottish Government Health Department from 2004 – predates the Human Tissue (Scotland) Act 2006 and would benefit from a review and update to ensure that it is fit for purpose. **The Scottish Government should undertake to review and update HDL2004/51, working with HM Revenue and Customs and NHSBT as necessary. (Recommendation 9)**

[4] Scottish Health Dept Letter 2004/51 - http://www.show.scot.nhs.uk/sehd/mels/HDL2004_51.pdf

4.20 It is important that everybody in Scotland who wishes to donate their organs or tissues after their death has every opportunity to do so. Individuals who live in remote or rural locations, or on any of the Scottish islands, can be disadvantaged at present due to the lack of access to the specialist intensive care facilities which are required to enable donation to proceed. Donation should be a core activity for all parts of the NHS. Accordingly, **the Scottish Government and the Scottish Transplant Group should look at options to ensure that individuals who live in remote parts of Scotland are able to donate if they wish to do so. Consideration should be given to transportation arrangements to enable potential donors to be moved to hospitals which can facilitate donation if necessary and appropriate. (Recommendation 10)**

PRIORITY 3: MAKING EVERY DONATION COUNT

Introduction

5.1 It is important that once an individual has taken the step of signing up to the NHS Organ Donor Register (or otherwise making their wish to donate known) the NHS does all that it can to ensure that such a wish is fulfilled; that as many organs as possible can be donated; and that those organs are in the best possible condition for transplantation. Every donation should count.

5.2 We know that current practices may not be optimising the number of organs that can be donated, nor ensuring that donated organs are in the best possible condition. This is a complex area, relating to how different clinical specialities within the NHS interact with each other, and involving the time and commitment of professionals who may not frequently have to deal with donation. If we are to ensure that every donation counts current shortcomings must be tackled.

5.3 We also know that organs that are donated may not be successfully placed and that there is variation in the willingness of transplant centres to accept organs, with some centres taking a more risk-averse approach in certain circumstances.

5.4 Many of these issues can only be successfully addressed and performance improved through good quality data monitoring. NHSBT captures a range of data on these issues which can be used to identify reasons for donations not proceeding.

Where are we?

5.5 While Scotland currently performs well in terms of progressing donation (with an average time of 10.5 hours for the DBD donation process and an average time of 8.7 hours for the DCD donation process), we continue to see families retracting their authorisation due to the length of the donation process. In 2012/13, 70 Scottish families declined organ donation. Amongst these families the most prevalent reason for declining (21 families) was the estimated length of donation process. (Of the 21 patients, six had joined the NHS Organ Donor Register in life). In addition, two families who initially authorised donation changed their mind and retracted authorisation once the donation process was underway due to the length of that process.

5.6 NHSBT currently manages the UK-wide potential donor audit (PDA), a system to capture a range of information around potential donors, their management, and outcomes in each case. The PDA has the potential to be a very strong tool to aid both the current process of donation, and to drive future developments by providing accurate data on donation activity. There are however a number of limitations with the PDA as it currently operates, giving rise to inaccuracies and insufficiently robust data in the potential DCD group.

5.7 NHSBT has committed to reviewing the PDA, but this work has stalled or slowed as a result of other pressures. The Scottish Transplant Group has previously expressed concern at the lack of progress with the review of the PDA and the Scottish Intensive Care Society (SICS) wrote to NHSBT in December 2012 to set out

its concerns at the lack of progress with the review, and to urge NHSBT to prioritise this work.

Key actions

5.8 Given the UK-wide co-ordination of activity around the process of retrieving and offering organs for transplantation, Scotland needs to work in close partnership with NHSBT and the other UK Departments on this issue. The Scottish Transplant Group will support delivery of the relevant priority actions set out in the NHSBT UK Strategy.

5.9 In order to streamline the process of offering of organs, and in order to reduce the amount of time that families need to wait for the donation process to complete, there is an urgent need for a simultaneous electronic offering system to streamline offering. This has the capacity to quicken the process significantly – US colleagues have reported that a similar mechanism, introduced five years ago, „transformed life‟ for them. **The Scottish Transplant Group and Scottish Government should work with NHSBT and the other UK Departments to encourage development and introduction of a system of simultaneous electronic offering. (Recommendation 11)**

5.10 The North East NHSBT Region (covering the north east of England) currently operates a system whereby transplant clinicians respond rapidly to SNODs who triage the initial referral of donors from the regional Critical Care and ED Departments. Experience in Newcastle suggests that limiting calls to local transplant centres streamlines the process significantly. The speed of response results in increased referrals and ultimately an increased number of donors. **The Scottish Transplant Group should review the experience from the North East Region, and consider rolling out a similar system within Scotland, to streamline the donation process. (Recommendation 12)**

5.11 The current system of organ donation and transplantation can only be effectively and robustly evaluated, and areas for improvement identified, if good quality data is available. The Scottish Transplant Group supports the position of the Scottish Intensive Care Society that NHSBT should prioritise the review of the PDA. **The Scottish Government and the Scottish Transplant Group should work with NHSBT to ensure that review of the Potential Donor Audit (PDA) is prioritised, and should continue to support the Scottish Intensive Care Society and College of Emergency Medicine representation on the NHSBT Potential Donor Audit sub-group. (Recommendation 13)**

5.12 An ongoing follow-up service for donor families is provided by the Specialist Nurse team and, where it is required, this includes an evaluation of the service, annual letters, remembrance services and other activities. Continuing engagement with donor families after the donation has taken place is an important part of the SNODs duties. Such families also can contribute significantly, if they wish to do so, to public understanding of the impact of donation of bereaved families. **The Scottish Government and the Scottish Transplant Group should work with NHSBT and others to provide a national gathering on alternate years to support donor families. (Recommendation 14)**

5.13 Another facet of making every donation count is ensuring that the transplants that take place are as successful as possible. Good after-care is key to ensuring successful patient outcomes. With the number of transplant operations increasing, and better survival rates, the number of patients requiring post-transplant care is growing rapidly. Transplant recipients in Scotland should already be receiving optimal post-transplant care, but **the Scottish Transplant Group should continue to monitor after-care requirements across Scotland, as well as relevant developments in evidence and research, to ensure transplant recipients receive the support that they need. Consideration should be given to working with primary care and other parts of the NHS to raise awareness on longer-term post-transplant management. (Recommendation 15)**

PRIORITY 4: ENSURING ALL PARTS OF NHSSCOTLAND ARE KNOWLEDGEABLE ABOUT AND SUPPORT DONATION AND TRANSPLANTATION

Introduction

6.1 As stated elsewhere, organ donation and transplantation are complex and multi-faceted issues and give rise to serious ethical and legal considerations. It is vital that the general public – whether wishing to be a donor or not – are reassured that appropriate safeguards are in place to ensure the wishes of individuals will be respected. Likewise, professionals need to have a legal and ethical framework upon which they can base the decisions they take in what may often be very difficult circumstances.

6.2 As well as having the appropriate frameworks in place there is a role for the NHS as a whole to champion and support donation and transplantation. Given the significant benefit to individuals and the NHS as a whole, that transplantation can bring, such support should be readily forthcoming. However, the reality is that for many professionals donation events are rare in a career. Many professionals will never be involved with patients who may benefit from transplantation and this whole area of work may be seen as peripheral. It is the role of government, NHSBT and the donation and transplant community to provide the information and education to challenge these perceptions. It the responsibility of NHS managers to champion and support donation and transplantation locally. Lessons from other parts of the world show that to increase donation rates the whole health system, and all parts of individual hospitals, should be knowledgeable about and embrace and support donation and transplantation. This is known as the „whole hospital‟ approach.

6.3 Organ donation and transplantation in Scotland is underpinned by the Human Tissue (Scotland) Act 2006. This legislation sets out the basis upon which individuals can authorise that their organs can be donated and used for transplantation after death, as well as a range of provisions relating to other aspects of donation and transplantation.

6.4 Other legislation is also relevant to donation – particularly the Adults with Incapacity (Scotland) Act 2000. This Act sets out provisions in relation to individuals who have lost capacity for any reason. Such loss of capacity might relate to accidents or serious injuries that leave an individual in circumstances where further treatment, both family and clinicians agree, would be futile. Their death, following the withdrawal of life-sustaining treatment, is inevitable. However, until death has actually been pronounced, the provisions of the Adults with Incapacity (Scotland) Act 2000 apply. The provisions of the Human Tissue (Scotland) Act 2006, apply only after death.

6.5 The UK Donation Ethics Committee and the Scottish Ethics Group (a sub-group of the Scottish Transplant Group) routinely consider legal and ethical issues that arise in relation to transplantation, and both groups make recommendations or provide advice to the UK or Scottish transplant communities as required.

Where are we?

6.6 The legal and ethical framework which underpins organ donation and transplantation in Scotland appears to be generally robust. There are however specific areas where further work may be useful to remove ambiguity. In particular, given the growth in DCD donation, there are issues relating to more invasive procedures which can be undertaken to support DCD, and how these relate to the interplay between the Adults With Incapacity (Scotland) Act, and the Human Tissue (Scotland) Act. Scotland"s Chief Medical Officer provided some initial clarification on these issues in a letter to the service in 2010[5] (further clarified in a follow-up letter in 2012[6]), but the letter did not go as far as to provide a general solution. There are complex legal and ethical issues involved that would require full public consultation before any clarification to guidance or amendment to law can be made.

6.7 Following the Organ Donation Task Force, a number of significant changes were made to improve the donation and transplantation infrastructure in Scotland, including:

- establishment of a donation committee in each mainland NHS Board with links to the Island Boards;
- establishment of a Clinical Donation Champion (now referred to as Clinical Leads for Organ Donation) in each of the donating hospitals in Scotland; and
- strengthening the network of donor transplant co-ordinators (now referred to as Specialist Nurses for Organ Donation), by appointing seven additional co-ordinators.

6.8 In spite of these infrastructure developments it is still clear that more can be done. The wide variation in donation rates across NHS Boards in Scotland (see chart 1 in the Introduction to this Plan) is evidence of that. We also know that there is more work to be done locally to ensure all parts of the NHS fully embrace donation and transplantation.

Key actions

6.9 The increasing contribution that DCD programmes now make to organ donor numbers has highlighted the need for further clarification about the nature of the interventions relating to organ donation that can properly be undertaken as part of those programmes. Although initial clarification was offered in advice from the CMO in 2010 and 2012, clinicians require specific and standardised advice. **The Scottish Government, working with the Scottish Transplant Group, should undertake to develop such advice for clinicians, and address any legal issues there may be. A full public consultation should be undertaken prior to any advice being issued, or prior to any legislative change. (Recommendation 16)**

6.10 Although a lot of work has been done to develop the donation and transplantation infrastructure as a result of the ODTF, there is evidence that more work is needed. Organ donation should be embraced as core business for all parts of

[5] CMO letter 2010/11 - http://www.sehd.scot.nhs.uk/cmo/CMO(2010)11.pdf
[6] CMO letter 2012/08 - http://www.sehd.scot.nhs.uk/cmo/CMO(2012)08.pdf

the NHS, and this can only succeed through the efforts of local managers, clinicians and nursing staff. **The Scottish Government and the Scottish Transplant Group should review local Organ Donation Committees and the work of Clinical Leads for Organ Donation, to determine whether or not the current infrastructure is effective, and to determine which approaches can best embed organ donation as core business for all. (Recommendation 17)**

6.11 It is important that the success of the NHS in Scotland in increasing rates of donation and numbers of transplants is recognised. Equally it is important that we are open about the areas of challenge, to ensure we target effort and resource where it can have the biggest benefit. **The Scottish Government should publish an annual report card on four or five key national measures on organ donation. (Recommendation 18)** Such a report card will ensure that clear information is available on the performance of NHS Boards in Scotland, but will also serve to increase awareness amongst the public and professionals in relation to organ donation and transplantation.

6.12 The „whole hospital‟ approach, which has been successful in other countries, may be a useful approach in Scotland. **The Scottish Government, working with the Scottish Transplant Group, should seek to pilot in one hospital a 'whole hospital' approach to organ and tissue donation. That pilot should be fully evaluated and all lessons learned. (Recommendation 19)**

PRIORITY 5: ENSURING THE PUBLIC IN SCOTLAND IS INFORMED AND ENGAGED ABOUT DONATION AND TRANSPLANTATION

Introduction

7.1 Organ donation and transplantation are issues of significant public, political and media interest. It is vital that the public in Scotland feels informed and engaged about all aspects of organ donation and transplantation. It is important that all parts of society have the opportunity to engage with any debate on policy.

7.2 It is also important that the generosity of donors both deceased and living, continues to be recognised and commemorated by government and society.

Where are we?

7.3 As detailed elsewhere, the Scottish Government has delivered national awareness-raising campaigns on an annual basis over the recent past. The Scottish Government has also established a Scottish specific website to support these campaigns, and has produced a schools information pack which has been well reviewed. It also produced an information leaflet to help people understand what they need to do if they want to donate their organs or tissue after they die. 750,000 copies of this were circulated to GP surgeries, community pharmacies and public libraries across Scotland. This material is in addition to the very good material available from NHSBT and other sources. Therefore, many sources of information are available for those interested in learning more about organ donation and transplantation. The Scottish Government campaign and the other sources of information will have contributed to the increase in the number of people signing up to the NHS Organ Donor Register in Scotland.

7.4 It is, however, important that the public and professionals are not simply passive recipients of information about organ donation – they should have an opportunity to provide views and shape policy and NHS practice. The Scottish Transplant Group includes representatives from donor families and transplant recipients, and the Scottish Government has regular engagement with the Scottish Patients Association on donation and transplantation issues. However, there has been no general public consultation on issues within this sphere since the passage of the Human Tissue (Scotland) Act 2006 more than seven years ago. There are important changes to policy or practice which could be introduced and which may have a beneficial impact on donation numbers in Scotland, but the Scottish public has not had the opportunity to provide a view on such approaches.

7.5 A permanent memorial to Scottish organ donors currently exists – the Loveseat in Kelvingrove Museum and Art Gallery in Glasgow. The memorial was originally developed by the West of Scotland Transplant Co-ordinators and funded by Kidney Research UK. The Scottish Government now funds this initiative and families of every deceased organ donor have the opportunity to add a silver leaf to the Loveseat to represent that donor‟s gift. There is limited space left on the Loveseat for new leaves to be added and a new memorial will soon be required.

Key actions

7.6 **The Scottish Government should undertake a full public consultation on potential approaches to increasing organ donation in Scotland. (Recommendation 20)**

7.7 Such a consultation should seek to establish public and professional views on specific issues such as (but not limited to):

- reciprocity (where those have signed up to the Organ Donor Register have priority for receiving an organ if they ever need one);
- financial contribution to funeral costs of donor families;
- a hard-line approach to self authorisation and family authorisation (where, if an individual has authorised that their organs can be used for transplantation, donation should proceed even without family support);
- required referral, where the NHS is required to refer any potential donor to SNODs; and
- measures to preserve the option of donation before speaking to a family member.

7.8 It is important that the gift of donation continues to be recognised. Some local donation committees around Scotland have commissioned artwork or memorials in recognition of the gift provided by donors. **The Scottish Government should undertake work to establish a new national memorial to organ and tissue donors. Such a memorial should be easily accessible. (Recommendation 21)**

Annex A

SUMMARY OF RECOMMENDATIONS

Priority 1: Increasing the number of people in Scotland who have made their wishes about donation known	
1a	The Scottish Government should continue to fund and deliver high-profile organ donation awareness-raising campaigns.
1b	The Scottish Government should ensure that proportionate targeted awareness-raising and education work continues with BAME and other relevant communities in Scotland, linking up to similar work across the UK as appropriate.
2	The Scottish Government should await evaluation of the move to „opt-out" in Wales before making any decision about the introduction of opt-out in Scotland.
3	The Scottish Government should ensure that the schools pack continues to be maintained and updated as necessary, and consideration should be given to providing the pack in other accessible formats, such as in e-book format.
Priority 2: Increasing the availability of organs	
4a	The Scottish Transplant Group should work with NHS Boards to develop tangible approaches to minimising and eliminating missed referrals, working in partnership with the Scottish Government, NHSBT and others.
4b	The Scottish Government should publish data on an annual basis detailing the number and type (DBD and DCD) of potential referrals that have been missed and in which NHS Board areas, to support NHS Boards in identifying and rectifying potential barriers to referral. Such data, which could also include tissue donation data should be published in the annual donation report card (see Recommendation 18).
5	NHS Boards and clinicians should ensure that all discussions with family members about the potential for donation involves a SNOD. The Scottish Transplant Group should monitor data on the rate of family refusals and report annually to Scottish Ministers.
6	The Scottish Transplant Group should continue to work closely with the Crown Office and the Scottish Fatalities Investigation Unit (SFIU) to ensure that Fiscals have the information they need to make informed decisions about donation. Such work should involve annual training days involving the criminal justice and transplant communities.
7	The Scottish Transplant Group and the Scottish Government should continue to support the DCD category II pilot in Edinburgh. That pilot should be fully evaluated and lessons learned and disseminated across the UK. If the pilot is successful consideration should be given to operating similar schemes in other parts of Scotland – although such schemes may only be viable in Edinburgh and Glasgow, where there is rapid access to large emergency departments and a local organ retrieval team.
8	The Scottish Government should ask National Service Division of NSS to look at the potential risks and benefits of moving to national commissioning of kidney transplantation in Scotland.
9	The Scottish Government should undertake to review and update HDL2004/51, working with HM Revenue & Customs and NHSBT as necessary.
10	The Scottish Government and the Scottish Transplant Group should look at options to ensure that individuals who live in remote parts of Scotland are able to donate if they wish to do so. Consideration should be given to transportation arrangements to enable potential donors to be moved to hospitals which can facilitate donation if necessary and appropriate.

Priority 3: Making every donation count	
11	The Scottish Transplant Group and the Scottish Government should work with NHSBT and the other UK Departments to encourage development and introduction of a system of simultaneous electronic offering.
12	The Scottish Transplant Group should review the experience from the North East of England Region, and consider rolling out a similar system within Scotland, to streamline the donation process.
13	The Scottish Government and the Scottish Transplant Group should work with NHSBT to ensure that review of the Potential Donor Audit (PDA) is prioritised, and should continue to support the Scottish Intensive Care Society and College of Emergency Medicine representation on the NHSBT Potential Donor Audit sub-group.
14	The Scottish Government and the Scottish Transplant Group should work with NHSBT and others to provide a national gathering on alternate years to support donor families.
15	The Scottish Transplant Group should continue to monitor aftercare requirements across Scotland, as well as relevant developments in evidence and research, to ensure transplant recipients receive the support that they need. Consideration should be given to working with primary care and other parts of the NHS to raise awareness on longer-term post-transplant management.
Priority 4: Ensuring all parts of NHSScotland are knowledgeable about and support donation and transplantation	
16	The Scottish Government, working with the Scottish Transplant Group, should undertake to develop such advice for clinicians, and address any legal issues there may be. A full public consultation should be undertaken prior to any advice being issued, or prior to any legislative change.
17	The Scottish Government and the Scottish Transplant Group should review local Organ Donation Committees and the work of Clinical Leads for Organ Donation, to determine whether or not the current infrastructure is effective, and to determine which approaches can best embed organ donation as core business for all.
18	The Scottish Government should publish an annual report card on four or five key national measures on organ donation.
19	The Scottish Government, working with the Scottish Transplant Group, should seek to pilot in one hospital a „whole hospital" approach to organ and tissue donation. That pilot should be fully evaluated and all lessons learned.
Priority 5: Ensuring the public in Scotland is informed and engaged about donation and transplantation	
20	The Scottish Government should undertake a full public consultation on potential approaches to increasing organ donation in Scotland.
21	The Scottish Government should undertake work to establish a new national memorial to organ and tissue donors. Such a memorial should be easily accessible.

Annex B

ORGAN DONATION TASK FORCE RECOMMENDATIONS

<table>
<tr><th>Recommendation</th><th>Progress In Scotland</th></tr>
<tr><td>1. A UK-wide Organ Donation Organisation should be established.</td><td rowspan="2">NHSBT undertook an internal reorganisation in order to form the Organ Donation and Transplantation Directorate with a remit coordinating organ donation and transplantation across the UK. It operates in Scotland under an income generating agreement with Scottish Government.</td></tr>
<tr><td>2. The establishment of the Organ Donation Organisation should be the responsibility of NHS Blood and Transplant.</td></tr>
<tr><td>3. Urgent attention is required to resolve outstanding legal, ethical and professional issues in order to ensure that all clinicians are supported and are able to work within a clear and unambiguous framework of good practice. Additionally, an independent UK-wide Donation Ethics Group should be established.</td><td>The Scottish Transplant Group established an ethics sub-group which works closely with the UK Donation Ethics Committee, to give consideration to complex ethical and legal issues. In 2010 it published guidance on legal issues relevant to donation following cardiac death and provided updated advice in 2012.</td></tr>
<tr><td>4. All parts of the NHS must embrace organ donation as a usual, not an unusual, event. Local policies, constructed around national guidelines, should be put in place. Discussions about donation should be part of all end-of-life care, when appropriate. Each Trust should have an identified Clinical Donation Champion and a Trust Donation Committee to help achieve this.</td><td>The Scottish Government gave strong support for implementation of the Taskforce recommendations, not least by including a reference to them in the Better Health, Better Care Action Plan. Organ Donation Committees have been established in all mainland NHS Boards with links established to the Island Boards and Clinical Leads for Organ Donation have been appointed in all NHS Boards.</td></tr>
<tr><td>5. Minimum notification criteria for potential organ donors should be introduced on a UK-wide basis. These criteria should be reviewed after 12 months in the light of evidence of their effect, and the comparative impact of more detailed criteria should also be assessed.</td><td>A Professional Development Programme centred on best evidence was delivered to support Clinical Leads and Committee Chairs. The master class covering Authorisation took account of this recommendation which has proved challenging in Scotland. In Spring 2013 NHSBT produced a Strategy for Identification and Referral of potential donors, endorsed by the Scottish Transplant Group. This is currently being revisited within the Scottish Collaborative network. Whilst the referral rate of potential donors has increased over the five years this remains an area in progress particularly in regard to donation after circulatory death where Scotland‟s performance remains poor in comparison to the UK average.</td></tr>
<tr><td>6. Donation activity in all Trusts should be monitored. Rates of potential donor identification, referral, approach to family and consent to donation should be reported. The Trust Donation Committee should report to the Trust Board through the Clinical Governance process and the</td><td>Regular information is available, via NHSBT. The potential donor audit (PDA) allows us to monitor a range of measures and data on donation and transplantation. NHSBT provides biannual reports for each NHS Board.</td></tr>
</table>

Medical Director, and the reports should be part of the assessment of Trusts through the relevant healthcare regulator. Benchmark data from other Trusts should be made available for comparison.	
7. Brainstem death testing should be carried out in all patients where brainstem death is a likely diagnosis even if organ donation is an unlikely outcome.	The diagnosis of death by neurological criteria is not undertaken in all patients where brainstem death is likely. In Scotland this occurs around 73% of the time. The UK average is 79%. We continue to monitor this complex area of clinical practice.
8. Financial disincentives to Trusts facilitating donation should be removed through the development and introduction of appropriate reimbursement.	Not applicable to Scotland (there never were disincentives in Scotland).
9. The current network of donor transplant co-ordinators should be expanded and strengthened through central employment by a UK-wide Organ Donation Organisation. Additional co-ordinators, embedded within critical care areas, should be employed to ensure a comprehensive highly skilled, specialised and robust service. There should be a close and defined collaboration between donor co-ordinators, clinical staff and Trust Donation Champions. Electronic on-line donor registration and organ offering systems should be developed.	All Specialist Nurses for Organ Donation were TUPE transferred to NHSBT employment and a regional Scottish Headquarters established in central Scotland. An additional seven Specialist Nurses for Organ Donation were appointed and fully embedded in critical care areas. Electronic on-line donor registration and organ offering systems fully implemented.
10. A UK-wide network of dedicated Organ Retrieval Teams should be established to ensure timely, high quality organ removal from all heart beating and non-heart beating donors. The Organ Donation Organisation should be responsible for commissioning the retrieval teams and for audit and performance management.	This recommendation is modelled on the practice in Scotland of a single national retrieval team and therefore, did not apply to Scotland. Commissioning of the Scottish organ retrieval team transferred from National Services Division to NHSBT.
11. All clinical staff likely to be involved in the treatment of potential organ donors should receive mandatory training in the principles of donation. There should also be regular update training.	A professional development programme for CL-ODs, SN-ODs and Donation Committee Chairs established by NHSBT. In addition, the Scottish Government, working in partnership with NHSBT, has developed an ongoing advanced clinical communications course for clinical staff likely to be involved in breaking bad news to the families of potential organ donors.
12. Appropriate ways should be identified of personally and publicly recognising individual organ donors, where desired. These may include national memorials, local initiatives and personal follow-up to donor families.	In Scotland there has for some time been a national memorial for organ donors (the Love seat in Kelvingrove Museum), and we are currently in the process of establishing a new memorial, to be located in the Royal Botanic Garden, Edinburgh.

13. There is an urgent requirement to identify and implement the most effective methods through which organ donation and the „gift of life" can be promoted to the general public, and specifically to the Black and Minority Ethnic population. Research should be commissioned through Department of Health Research and Development funding.	The Scottish Government has consistently run high-profile public awareness campaigns to raise awareness of organ donation, to encourage people to join the NHS Organ Donor Register and to make their loved ones aware of their wishes. Tailored awareness-raising and information giving activity is undertaken with BAME communities through high-profile multicultural events throughout Scotland. We recognise, due to changing demographics within the Scottish population, additional ethnic minority groups may need to be engaged with in the future.
14. The Department of Health and the Ministry of Justice should develop formal guidelines for coroners concerning organ donation.	Not relevant to Scotland, although we have done a lot of work with the Crown Office and Procurators Fiscal to ensure that there are no unnecessary donation refusals. This is an ongoing task. The Scottish Transplant Group supports a regularly reviewed agreement with the Crown Office and Procurator Fiscal service outlining respective responsibilities. The guidance is again under review to take account of the COPFS support in establishing the Category II programme pilot in Edinburgh.

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