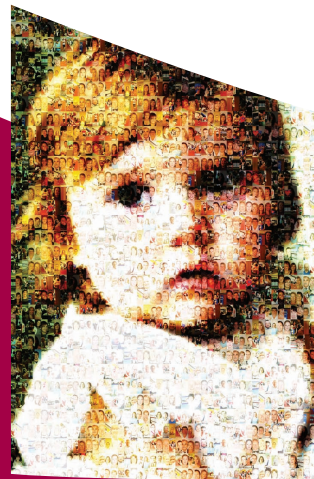


Working together to save lives

*The Organ Donation Taskforce
Implementation Programme's
Annual Report, 2008/09*



Department of
**Health, Social Services
and Public Safety**

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AN ROINN

**Sláinte, Seirbhísí Sóisialta
agus Sábháilteachta Poiblí**

MANNYSTRIE O

**Poustie, Resydënter Heisin
an Fowk Siccar**



Llywodraeth Cynulliad Cymru
Welsh Assembly Government

DH INFORMATION READER BOX

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Organ donation occurs at a time of great emotional distress. The terminology and phraseology in this report are necessarily factual, and might appear unsympathetic to those most closely affected by organ donation. This dispassionate reporting of events and outcomes should not be taken as disrespectful to deceased donors or their families, or to the amazing gift that they make.

Management of the NHS is devolved to the health departments of the four countries of the UK, with each country having slightly differing structures for the management and accountability of NHS services. For simplicity, this report uses language that refers to the English structure, while noting that there are equivalent structures in the other countries.

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Foreword



In January 2008, the Organ Donation Taskforce published its report *Organs for Transplants*. This report set out 14 recommendations, collectively designed to meet the challenges that we face and

achieve a 50% increase in donation within five years.

We are now in the implementation phase and this current report records our activity up to the end of March 2009. It should be read as a work in progress, because inevitably the initiatives we are putting in place will take time to bed in. The issues surrounding organ donation are complex, and cover clinical practice, the management and structure of teams and organisations, and some acutely sensitive moral and ethical issues.

So we have big challenges and high ambitions. Nevertheless, I am greatly encouraged by the progress that we have made so far. In particular, the ongoing appointment of clinical leads across hospital trusts is of huge significance.

These appointments go right to the heart of the *Organs for Transplants* report, especially the need to make donation a usual and integral part of our health service culture. We now have senior clinicians championing the cause of donation and providing strategic leadership and expertise where it is most needed.

Work is also in hand to create a national organ donation organisation able to map out future strategy and with a dedicated training programme. The national network of donor transplant co-ordinators, centrally managed but working alongside colleagues in individual hospitals, is fundamental to making donation usual throughout the NHS.

I would like to pay tribute to the commitment of NHS Blood and Transplant and all our partner organisations in building this cohesive, integrated organisation. In the years to come it will make a massive difference to the landscape in which we operate.

It is early days. But with the continuing commitment and hard work of our many stakeholders we have made a sound start. Working together, we can make a lasting difference and transform patients' lives.

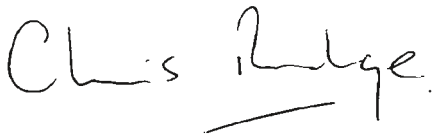
Mr Chris Rudge FRCS

**Chair, Organ Donation Taskforce Programme
Delivery Board and National Clinical Director
for Transplantation**

Vision for organ donation and transplantation

We wish to see organ donation become a usual rather than unusual event as part of end-of-life care across the NHS.

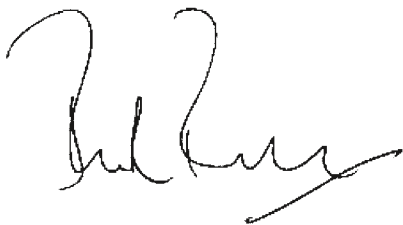
Each individual should be given the choice and opportunity to offer their organs for the purposes of transplantation after their death. This choice should not be denied by the assumptions of NHS staff or a lack of facilities and infrastructure.



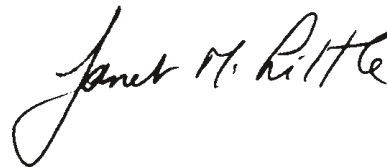
Mr Chris Rudge
National Clinical Director for Transplantation
(England)



Dr George Findlay
Chair, Wales Organ Donation
Implementation Group



Mr John Forsythe
Lead Clinician for Organ Donation and
Transplantation (Scotland)



Dr Janet Little
Chair, Northern Ireland Organ Donation
Implementation Group



Boosting organ donation, saving lives

The challenge addressed by the Organ Donation Taskforce Implementation Programme

‘The commitment is beginning to pay off, with many of the major structural changes already well under way.’

Transplantation is an important part of modern medicine and, in some cases, the only treatment for a range of conditions.

Important medical innovations have transformed the outcomes for patients and aided the work of doctors. For example, clinical and critical care procedures have been improved and better anti-rejection drugs introduced.

Transplants can transform the quality of people’s lives, but are currently limited by the availability of organs for transplants.

The facts are as follows:

- Nearly 10,000 people need a transplant – a figure that is rising by about 8% a year.
- Of these, 1,000 die every year waiting for a transplant.
- Black and minority ethnic people are in ‘double jeopardy’: they are three times more likely to need a kidney transplant, but are faced with a much smaller number of potentially matching donors.

The Organ Donation Taskforce, established by Health Minister Rosie Winterton, began work in December 2006 with a remit to identify the obstacles to organ donation, and to make recommendations that would address these challenges.

The Taskforce’s report *Organs for Transplants* sets out a clear vision for how to improve this situation.

The four countries of the UK accepted the Taskforce’s recommendations in full, and have come together in a co-ordinated programme to turn the Taskforce’s vision into a sustainable reality. The programme (which contains 26 separate pieces of work) addresses the 14 recommendations of the original Taskforce report.¹

The commitment is beginning to pay off, with many of the major structural changes already well under way. This report details the progress made in the first year of the programme, and the improvements that we have seen in the number of donors, the number of transplants and the number of people joining the Organ Donor Register.

‘10,000 people need a transplant – a figure that is rising by about 8% a year.’

¹ Department of Health (2008) *Organs for Transplants: A report from the Organ Donation Taskforce*, pages 7–19.

Timeline 2008/09



January

The report of the Organ Donation Taskforce, *Organs for Transplants*, is published. It makes 14 recommendations and is accepted in full by the Government and welcomed by partner organisations.

Lynda Hamlyn joins NHS Blood and Transplant (NHSBT) as Chief Executive.

February

NHSBT starts a market research programme to inform the public campaign.

March

UK Transplant (UKT) starts early preparatory work, with projects on clinical leads, donor transplant co-ordinators and organ retrieval.

The Scottish Parliament holds a debate on the *Organs for Transplants* report and its recommendations.

A television advertising campaign to promote organ donation starts in Scotland.

April

Mr Chris Rudge is appointed as the first National Clinical Director for Transplantation by the Department of Health.

UK-wide reimbursement of hospitals for donation activity starts.

May

Dr Janet Little is appointed as Chair of the Northern Ireland Organ Donation Implementation Group.

Launch of the 'Donate Wales – Tell a Loved One' campaign.

June

The Organ Donation Taskforce Programme Delivery Board is set up, chaired by NHS Medical Director Professor Sir Bruce Keogh. Additional staff join UKT in preparation for the work ahead.

July

Sally Johnson is appointed as Director of Organ Donation and Transplantation at NHSBT.

August

Nearly 1,000 transplant recipients from across the UK demonstrate the life-changing gift of organ donation by coming together to compete at the 2008 Transplant Games in Sheffield, which is supported by the Department of Health.

September

Dr George Findlay is appointed as Chair of the Wales Organ Donation Implementation Group.

UKT changes its name to Organ Donation and Transplantation to reflect the Organ Donation Taskforce recommendation that NHSBT should be the UK-wide donation organisation.

October

The Welsh Assembly Government starts the public debate on an opt-out system for organ donation.

Meetings are held across Scotland with all NHS Board chief executives, chairs, and medical and nursing directors. All express their strong support for the programme's work.

South Thames is the first team of donor transplant co-ordinators to transfer to NHSBT.

November

The Royal College of Surgeons of England announces a national network of organ donation specialists, trained to improve skills in retrieving and transplanting organs.

The Scottish Transplant Group established a sub-group to examine and resolve the outstanding legal, ethical and professional issues.

The Organ Donation Taskforce publishes its report into the potential impact of an opt-out system in the UK.

December

The first 15 referrals of organs for transplantation are completed using the Electronic Offering System.

The first UK hospital-based Clinical Lead for Organ Donation, Dr Joyce Stuart, is appointed at Western General Hospital, Edinburgh.

Three new senior clinical staff are appointed to NHSBT. Professor James Neuberger joins as Associate Medical Director (Organ Donation and Transplantation), Mr David Mayer as Clinical Lead for Organ Retrieval and Dr Paul Murphy as National Clinical Lead for Organ Donation.



January

The number of people on the NHS Organ Donor Register reaches 16 million, 12 months earlier than planned.

A successful meeting is held to look at the training needs for healthcare staff around organ donation.

West Midlands is appointed as the lead strategic health authority for organ donation.

February

First UK-wide meeting of clinical leads for organ donation at the Royal College of Anaesthetists. The College's President attends for a short while to lend support to the initiative.

Mr John Forsythe is appointed as Lead Clinician for Organ Donation and Transplantation in Scotland.

March

A year on, the Taskforce is making 'good signs of progress', according to England's Health Minister Ann Keen. She reports:

'Successful recruitment campaigns have already added 39 new donor transplant co-ordinators and 20 more are hoped to be recruited in the coming months. At least 48 clinical donation champions are now in post, with more being appointed every week.'

Northern Ireland runs a campaign to promote organ donation.



A year of progress

Transplanting changes: the programme forges ahead

'It's a new life.'

Rashida Karbhari lived with renal failure for years



Rashida, 40, was diagnosed with end-stage renal failure at the age of 27.

'I was perfectly well – well I thought I was – and planning to go on holiday to India. They examined me and the doctor told me I couldn't travel. A day later I was told I had kidney failure.'

For the next year she was taking 'so many tablets'. In 1989 Rashida began dialysis – a tough weekly regime that was to last for over 11 years. Haemodialysis – where blood is taken from the body and cleaned in a dialyser – disrupted her daily life.

Third time lucky

The wait for a transplant seemed interminable and there were two disappointments during the search for a tissue match. Finally, a kidney transplant transformed Rashida's quality of life.

'We can travel more now. I can do activities again, like going to the park with the kids. I've always liked being fit and healthy and now I can go swimming and go for long walks. It feels good to walk so much and not get tired. It's a new life!'

The Organ Donation Taskforce Implementation Programme's first year has seen us make great progress. Within months of publishing the *Organs for Transplants* report in January 2008, we were pushing ahead on the 26 separate projects needed to deliver the Taskforce's 14 recommendations.

We recognised that the success of the programme required us to focus on leadership, system redesign, funding and implementation so as to establish the essential foundations for future progress.

Leadership

Our most important early work was to put in place the right leadership for both the programme and for those NHS professionals working in frontline roles. Professor Sir Bruce Keogh, Medical Director of the NHS, was appointed as the senior person with responsibility for leading the implementation work.

By June 2008, a Programme Delivery Board was established. It brought together representatives from the four UK health departments and NHS Blood and Transplant alongside those from the medical Royal Colleges, professional bodies, NHS managers and regulatory bodies.

Working together

The Organ Donation Taskforce recommended that every hospital should have a clinical donation champion (CDC), who develops a close, collaborative relationship with their local donor transplant co-ordinators (DTCs). Here is how one hospital in Scotland is meeting this challenge.

The Western General Hospital in Edinburgh has appointed a CDC, one of 50 UK hospitals who have already made this important step towards increasing organ donation.

The role, now called 'Clinical Lead for Organ Donation', is a natural one for Joyce Stuart, Consultant in Intensive Care at the Western General since 2002 (pictured on the right). The unit has 16 beds and sees 800 patients a year, of whom about 30% are neurosurgical. There is therefore considerable potential for deceased donation following brain stem or cardiac death.



The hospital is very supportive of organ donation. Joyce believes that the key to their success is the relationship between the DTCs and consultants. 'It's down to the personality and negotiation skills of DTCs and being able to feed back the positive outcomes of organ donation.'

As the local link consultant, Joyce works closely with Liz Waite (pictured on the left), lead DTC and one of two who look after Western General Hospital.

One particularly rewarding joint task has been the auditing of all the non-heartbeating donors at the hospital since the programme started in 2005. 'Discussing the practical and ethical difficulties which have arisen at regular debriefing meetings has led to ongoing improvements in how the process is conducted,' says Joyce.

The success of the donor programme is down to good working relationships between DTCs and clinical staff, says Liz. The new clinical lead role will help these relationships significantly. 'The clinical leads will be able to do more work with peer group education and will be able to promote organ and tissue donation throughout the hospitals through the donation committees.'

It is the larger intensive care units that have the most difficulties, Liz points out. 'In some of the bigger hospitals it is difficult to find who you need to speak to. But with appointed clinical leads this line of communication will be much clearer. Hopefully, with the generosity of donors and their families and being able to feed back the positives to intensive care units, organ donation will continue to increase.'

Mr Chris Rudge was appointed as the first National Clinical Director for Transplantation in England, with Mr John Forsythe, Dr George Findlay and Dr Janet Little performing equivalent roles in Scotland, Wales and Northern Ireland respectively. To champion change and innovation within the NHS, NHS West Midlands was appointed as the lead strategic health authority for organ donation.

Leadership within frontline NHS services was identified by the Taskforce as a major catalyst of making organ donation usual rather than unusual. By the end of March 2009:

- senior clinicians had been appointed as clinical leads for organ donation in 80 out of 197 acute hospital trusts (or equivalent) across the UK;
- 16 out of 183 donation committees had been established;
- 20 out of 183 hospitals had non-clinical donation champions; and
- terms of reference had been put in place to set out the work of these individuals and committees.

To help reinforce the programme's work with frontline NHS staff, we planned a series of meetings for the summer and autumn of 2009, with clinicians and managers in the English strategic health authorities and in the other countries of the UK.

Service redesign

The Taskforce identified the need for a number of important changes to the structure and processes for dealing with organ donation and allocation nationally.

As recommended in *Organs for Transplants*, NHS Blood and Transplant (NHSBT) took over sole responsibility as the organ donation organisation for the UK. This was reflected in the renaming of UK Transplant as the Organ Donation and Transplantation Directorate.

NHSBT's frontline work also saw important changes. The Organ Donation and Transplantation Directorate took over responsibility for the national co-ordination, organisation and management of the UK's network of DTCs. Work started on enlarging the network of DTCs to ensure that each hospital has an identified DTC, working closely with the hospital's clinical team. By the end of March 2009, 97 DTCs and administrative support staff were in place, with recruitment continuing throughout 2009.

We have completed preparations to ensure that NHSBT's Electronic Offering System can be rolled out across the UK. This computer system provides DTCs and recipient co-ordinators with up-to-the-minute information about organ availability across the country, helping to ensure quicker, more efficient and co-ordinated donation activity.

To match these efforts, which are boosting the number of organs available for transplantation, a number of complementary projects are moving forward. These will ensure greater transplant service capacity, in line with increased organ donation.

A framework for a co-ordinated UK-wide system of organ retrieval teams was completed and a standard contract developed. The National Commissioning Group started working to ensure that transplantation capacity in English hospitals would match the expected increase in organ donation numbers. A UK-wide reimbursement programme was established to compensate hospitals for their teams' donor management work. A payment will be made every time a hospital supports a donor.

Funding

The substantial work going on, both locally and nationally, within the programme's 26 'project streams', requires adequate funding. In 2008/09, £16.5 million was allocated to the NHS for organ donation and transplantation, with a further £26.5 million allocated for 2009/10. An additional £500,000 was provided from the Department of Health to support implementation programmes and fund national events, including the UK Transplant Games and National Transplant Week.

Information

We want to ensure that everyone involved in organ donation – both frontline staff and central teams – is able to see the results of their actions. So a unified format was decided upon for the collection and communication of all donation activity. This information is then sent out to trust chief executives and clinical leads for organ donation twice a year, starting in the summer of 2009. This will enable local activity to be set against the national picture.

Organ donation activity was also included in the quality indicators, introduced this year as a result of the NHS Next Stage Review.

Making organ donation usual

The work of the Taskforce and the implementation programme has raised the profile of organ donation within the NHS and among the public.

Although the programme is still in its infancy, in the last year we have seen a record rise of 11% in deceased organ donor rates. That represents 90 extra donors and 174 extra transplants during the year. This was matched by a corresponding rise of 12% in the number of living donors.

Alongside these achievements, there has been a 6.5% increase in the number of people on the organ donor register, which now stands at 16.3 million people (more than one quarter of the UK's population).

Further work by the Taskforce

The Organ Donation Taskforce continued its work throughout 2008, publishing its second report, *The potential impact of an opt out system for organ donation in the UK*, in November 2008. This report concluded that an opt out system is not right for the UK at present, but that the progress of the implementation programme should be monitored to see whether the issue needs revisiting in future.

As part of this work, the Taskforce collected substantial amounts of information, particularly around public and professional attitudes to organ donation, which has helped to inform many of the projects carried out as part of the programme.

The year ahead

The first year of the Organ Donation Taskforce Implementation Programme has put in place the major structural changes recommended in the *Organs for Transplants* report. Many of these were substantially completed by March 2009.

In the coming year, our focus will move towards making sure that these structural changes – from the organ donation organisation itself to those around clinical leads and DTCs – start to produce lasting changes.

'In the last year we have seen a record rise of 11% in organ donor rates.'

Change agent

In-house co-ordinator Jo Coles reports on progress

I am a specialist nurse, an embedded donor co-ordinator at St George's Healthcare NHS Trust. Based on the neurointensive care unit, which has the greatest potential for donors, I cover all the sites daily. Gradually, colleagues are accepting the change from an office-based to a hospital-based co-ordinator.



I provide knowledge and leadership in all aspects of donation and high-quality care in the end-of-life care process, offering the option of donation as appropriate to families and supporting their decisions at extremely sad and stressful times.

Communication and interpersonal skills are essential. Without trustworthy relationships it is difficult for me to act as a change agent, maximising identification and referral.

Collecting and analysing information are vital in understanding the organisation's performance as well as my own. Data provides the evidence to introduce new measures and improve the donation process.

Doctors and nurses are beginning to challenge colleagues and encourage referral to the co-ordinator: brain stem dead individuals and all non-heartbeating donors are referred in a timely fashion. This allows for a well-planned approach to donation, and the co-ordinator is always present or makes the approach to families. For the years 2007 and 2008 we saw an increase from 12 to 18 consents.

The projects to clarify legal and ethical issues are progressing well, with new guidance being produced for coroners and NHS staff. A UK-wide donation ethics committee will consider the more complex issues facing the teams working in this area.

A new national lead for training will also address the issues around the training of key groups of frontline medical staff. This will pick up from the successful event in January 2009 which identified the different training needs for specific groups.

While this work goes on, a major public campaign to promote organ donation is planned by NHSBT in the autumn of 2009. There will also be proposals on how best to recognise the tremendous gift of life from organ donors and their families. Without their selflessness, none of this work would be possible.

Maximising and monitoring donation: bringing a donor family's perspective to help hospitals improve

One of the Taskforce's central recommendations is to make organ donation integral to healthcare culture. The formation of a donation committee is vital to this.



Barry Jenkins (pictured left) became involved in organ donation when his 24-year-old son Richard was suddenly admitted to hospital and sadly died 17 days later of a brain stem tumour.

'From the tragedy of the grief there was hope. The consultant oncologist said to us "Have you considered Richard as a donor?" It was like somebody had lit a candle in a darkened room. Strange to say, but it has been a positive experience.

'It has been such a help to us with our grief. We wanted to give something back. From that, I was asked by the Royal Berkshire Hospital to join their donation committee as chair.'

Barry explained the importance of this work for the hospital. 'If people want to promote organ donation, it is essential to have a committee that not only ensures that the policy is carried out, but that donation is maximised and monitored.'

The committee is a catalyst for bringing groups together, focusing on improving policies and raising awareness of organ donation, particularly among those who may never have considered it before. Barry already sees evidence of good progress, for example on staff training and education: 'You need to provide encouragement – in order to overcome the barriers and to keep moving forward.'

He has this advice for trusts setting up a donation committee: 'Set it up quickly and take it from there.' Frame objectives and define terms of reference. Have regular meetings during the formation stage and take a "softly, softly" approach when seeking to win people over.'

UK campaign boost for organ donation

The first major campaign in this country to promote public awareness and support for organ donation has been developed over the past year.

This multimedia campaign, planned by NHSBT for autumn 2009, is based on extensive qualitative and quantitative research as to why the support for organ donation among the UK public does not always translate into action.²

In the run-up to the campaign, the public is being asked to join the NHS Organ Donor Register through the Wall of Life, an interactive site also designed as a celebration of the 16 million people who are already registered.

Having joined the Register, people can then add their photo and a personal message to the Wall of Life to make up the image of Louisa McGregor-Smith (pictured below), a two-year-old whose life was saved by a heart transplant. People are being asked to help us spread the message about organ donation, by passing on details to their friends and families using social networks.

More than 10,000 people currently need a transplant in the UK. Of these, 1,000 – on average three a day – die every year because there are not enough donated organs. This stark truth has focused the communications strategy over the last year. Activities included the *Lifegivers* television series on BBC1, the launch of a single donation number and work to counter myths about organ donation.

To join the NHS Organ Donor Register via the Wall of Life, go to www.walloflife.org.uk



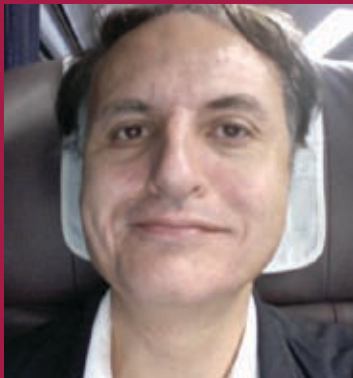
² While 90% of the UK population say that they support organ donation, only 27% have joined the NHS Organ Donor Register (market research on barriers to organ donation, 2003).

Other work to improve donation and transplantation

Across the UK, there has been important work to improve donation and transplantation. The health departments in each country are now developing their own initiatives, which work alongside the UK-wide remit of NHSBT.

Below, we showcase some examples which demonstrate our collective commitment to building upon the Taskforce's recommendations.

Cardiff Transplant Unit's 'defining moment'



Seven consortia of transplant units will provide the first UK-wide national organ retrieval service. Cardiff, in collaboration with Birmingham, will be one of these. Consultant Transplant Surgeon Mr Argiris Asderakis reports.

This is a defining moment for Cardiff. Especially when you consider the fact that we are one of only three non-liver centres selected for this role. This is the end result of our efforts to increase the profile of the unit. In the last few years we have:

- increased the number of transplants by 50% – the average number carried out between 2000 and 2006 was 84, in 2007/08 we reached 125;
- increased the number of organs retrieved in the region; and
- started pancreas transplantation and provided a pancreatic retrieval service for the whole of Wales.

Following the Taskforce's recommendations, it was decided that the donation process be overhauled. New organisational arrangements for retrieval were agreed, under the auspices of a directorate within NHSBT.

Following pilots and intensive negotiations between units, a new way of working will be advanced from April 2010. This will need significant resources and investment – funding linked to the implementation of the Taskforce recommendations. Each hospital will be allocated three sequential retrieval teams depending on its location.

So hopefully no hospital will have to wait more than three hours for an organ retrieval to happen. Meetings are taking place in order to firm up arrangements between the consortia, so that the whole of the UK is adequately covered.

Scotland: hard work begins to pay off

The Taskforce's recommendations have high-level political support, and Scotland's Cabinet Secretary for Health and Wellbeing has given the Scottish Transplant Group responsibility for implementing them.



The Taskforce saw the need for urgent action to resolve outstanding legal, ethical and professional issues, so as to give clinicians a clear framework of good practice. The Scottish Transplant Group has established a sub-group to follow this through. This met for the first time in November 2008, chaired by Dr Stephen Cole (pictured left), a leading member of the Scottish Intensive Care Society.

By March 2009, five of the 11 mainland NHS boards had donation committees. A great deal of related work was also under way across Scotland, including:

- preparations to transfer donor transplant co-ordinators to NHSBT employment and to recruit an additional six DTCs;
- discussions with NHS Quality Improvement Scotland about providing a national perspective on organ donation activity across all NHS boards;
- talks with educational leads regarding training packages for relevant NHS staff groups;
- discussions with interested representatives about the best method of increasing awareness of organ donation within the black and minority ethnic population; and
- production of a newsletter to ensure that the wider NHS in Scotland was kept informed of progress.

As Scotland has had its own nationwide organ retrieval team in place for some years, its organ retrieval arrangements will remain largely unchanged from April 2009, with the Scottish team responsible for all retrievals in Scotland. There will be additional retrievals in Northern Ireland and extra back-up for teams elsewhere in the UK.

All of this hard work is beginning to pay off: in 2008/09 there was a record number of organ donors in Scotland. There were 72 deceased organ donors – a rate of 14.1 donors per million of population, up from 9.8 donors per million in 2006/07.

Campaign boosts Northern Irish donor registrations



At the beginning of 2009, 320 people were waiting for an organ transplant in Northern Ireland. There were 435,069 names on the organ donor register, which represented just 23% of the province's population and the third-lowest regional percentage in the UK.

In January, the Northern Ireland Regional Implementation Group, chaired by Dr Janet Little (pictured left), learned that the Department of Health, Social Services and Public Safety would provide £145,000 from end-of-year monies to further their work within the financial year.

The group agreed that a publicity campaign – based on paid-for advertising – would be both effective and valuable. The aims were:

- to raise the public's awareness of the issue of organ donation in Northern Ireland;
- to make people think about what it might be like to be a patient waiting for a transplant; and
- to encourage people to sign up to the NHS Organ Donor Register.

An advertising campaign drawing on radio, newspaper and poster advertising was devised, using as its template an earlier, national campaign. The group's creative partner was the Central Office of Information, which used its expertise to frame a two-week campaign from mid-March.

Early indications are that this activity has paid off. Web-based and telephone registrations are double the normal rate, and overall, registrations were over 30% higher when compared to the same period the previous year.

Heather Reid, Project Manager of the Implementation Group, commented:

'This campaign was put together against very tight deadlines and worked well. It has raised awareness in Northern Ireland and set the scene for another national campaign in the autumn.'

Statistics

A successful first year

More donors, extra transplants – 16 million registered

The first year of the Organ Donation Taskforce Programme has seen a successful drive to increase the number of donors. The numbers of deceased donors are up 11% on the previous year. This led to 174 extra transplants from deceased donors. The number of people on the Organ Donor Register also rose by 6.5%, taking the number registered over 16 million for the first time.

The work to ensure that potential donors are identified, and that their families are given the choice to say whether they want to be a donor, is a key factor in the increase in deceased donors. This is particularly true among people donating after cardiac death, where numbers have risen by 35% over the last year.

However, the number of people donating following brain death has remained static, as improvements in intensive care practice and in public health (such as in stroke and road accidents) have led to a fall in the number of people who would be able to donate.

This trend towards falling numbers of people who could donate following brain death is also being seen in other countries. Improved care of critically ill patients is strongly welcomed. However, it prompts an ever greater challenge to meet the needs of the increased number of people requiring organ transplants as a result of such an improvement in care.

It therefore becomes even more vital to recognise and identify this diminishing number of patients whose death occurs when donation is a possibility, and to optimise all the steps that can lead towards donation.

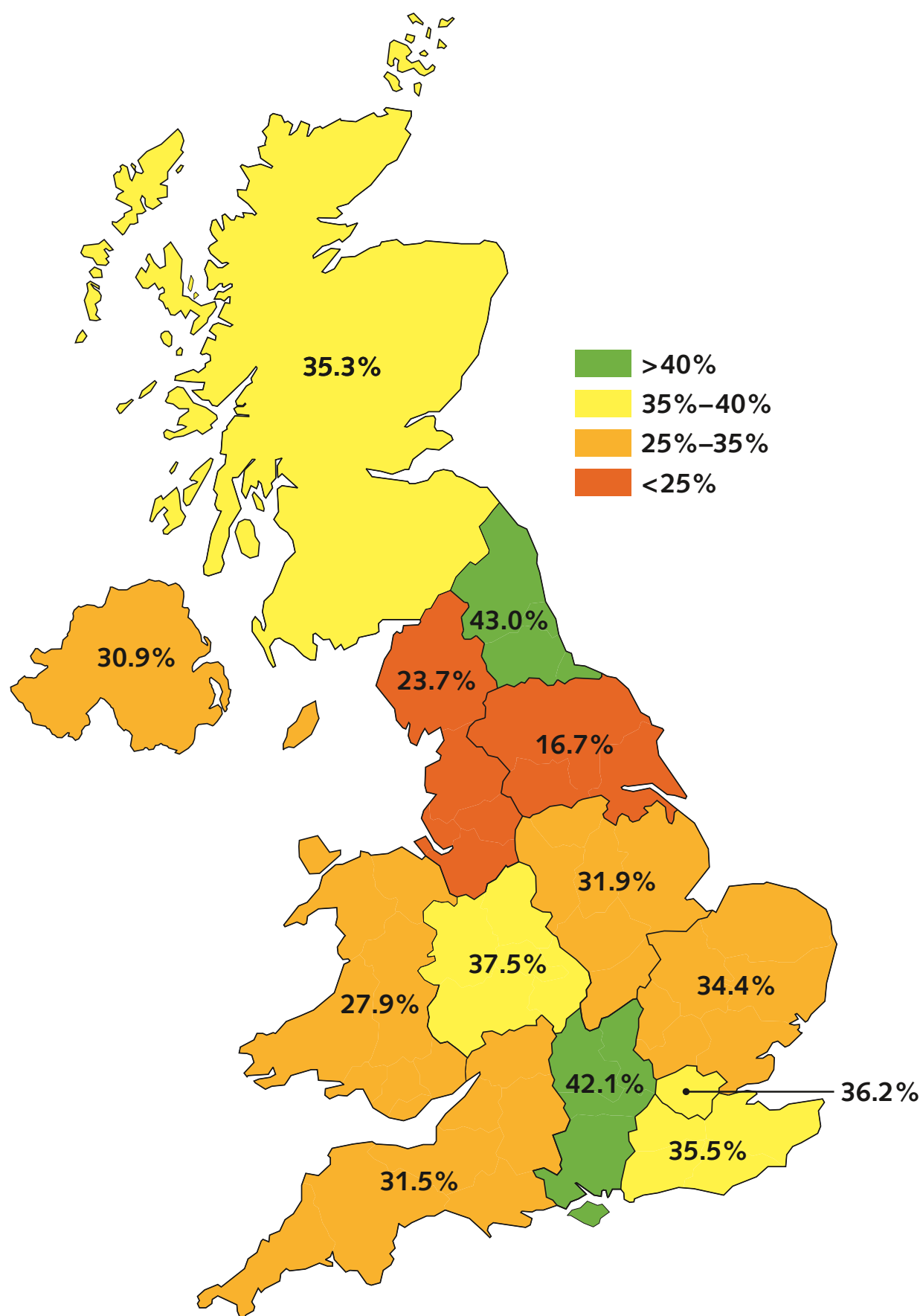
People who donate following brain death remain the 'gold standard' for organ donation. They are the only source of viable hearts after death and are able to provide much better livers for transplantation. The increase in donors following cardiac death is helping to increase the numbers of kidneys available for transplantation substantially, with the continuing development of programmes for donation following cardiac death. However, the limitations of this potential donor source need to be recognised.

Meeting the future challenge

Although not strictly within the scope of the Organ Donation Taskforce Implementation Programme, living donors play an important role in providing kidneys and, on occasion, other organs for transplantation. Living donors now provide the organs for nearly 1,000 transplants a year, with the numbers of both donors and transplants up by 12% on 2007/08.

A longer wait poses a challenge for us all. The growing waiting list shows the scale of the challenge faced by everyone working in organ donation and transplantation. One of the key factors behind this increase is the increasing incidence of kidney failure in the UK – particularly in the over-50 and black and minority ethnic communities.

Proportion of donors who go on to donate, 2008/09



It is worth noting that the waiting list does not represent the full extent of the need for organs for transplantation. It only contains those people who are clinically suitable at that moment should a suitable donor become available.

If an individual's condition deteriorates, or they develop an infection or other illness, then they can be suspended or removed from the list. Furthermore, the shortage of donated organs means that, sadly, not everyone who could benefit from a transplant even gets added to the waiting list.

Proportion of potential donors who go on to donate

	2008/09			2007/08		
Strategic health authority/country	Potential donors	Actual donors	Conversion rate (%)	Potential donors	Actual donors	Conversion rate (%)
NHS East Midlands	91	29	31.9	91	18	19.8
NHS East of England	244	84	34.4	157	54	34.4
NHS London	387	140	36.2	381	121	31.8
NHS North East	107	46	43.0	113	56	49.6
NHS North West	338	80	23.7	272	77	28.3
NHS South Central	159	67	42.1	163	52	31.9
NHS South East Coast	121	43	35.5	98	46	46.9
NHS South West	238	75	31.5	273	82	30.0
NHS West Midlands	192	72	37.5	189	67	35.4
NHS Yorkshire and the Humber	270	45	16.7	213	55	25.8
Scotland	184	65	35.3	152	48	31.6
Wales	122	34	27.9	121	45	37.2
Northern Ireland	68	21	30.9	59	22	37.3

Note: All data is from the NHSBT Potential Donor Audit as at 23 July 2009. Numbers of potential and actual donors include donation following brain death and donation following cardiac death. The conversion rate is the proportion of potential donors who go on to donate.

Donors in the UK

Financial year of donation	2008/09	2007/08		2003/04		1998/99	
	Number	Number	% change	Number	% change	Number	% change
After brain death	611	609	0.3	697	-12.3	708	-13.7
After cardiac death	288	200	44.0	73	294.5	30	860.0
Total deceased	899	809	11.1	770	16.8	738	21.8
Living	961	858	12.0	472	103.6	285	237.2
Total	1,860	1,667	11.6	1242	49.8	1,023	81.8

Note: All % changes are comparisons with the 2008/09 data

Active waiting list (as at 31 March)

Year	2009	2008		2004		1999	
	Number	Number	% change	Number	% change	Number	% change
Total	7,877	7,655	2.9	5,673	38.9	5,345	47.4

Note: The active waiting list only contains those people who are clinically suitable for immediate transplantation

People removed from the transplant list or who die while on the list

Financial year	2008/09	2007/08		2003/04		1998/99	
	Number	Number	% change	Number	% change	Number	% change
Removed from the transplant list	648	573	13.1	452	43.4	482	34.4
Died on the transplant list	423	536	-21.1	468	-9.6	530	-20.2
Total	1,071	1,109	-3.4	920	16.4	1,012	5.8

Transplants in the UK

Financial year of donation	2008/09	2007/08		2003/04		1998/99	
	Number	Number	% change	Number	% change	Number	% change
After brain death	1,976	1,952	1.2	2,255	-12.4	2,317	-14.7
After cardiac death	579	429	35.0	141	310.6	43	1,246.5
Total deceased	2,555	2,381	7.3	2,396	6.6	2,360	8.3
Living	961	857	12.1	471	104.0	285	237.2
Total	3,516	3,238	8.6	2,867	22.6	2,645	32.9

Note: 26 of the transplants in 2008/09 were from donors from outside the UK, who donated following brain death

Transplants per organ donor in the UK

Financial year of donation	2008/09	2007/08		2003/04		1998/99	
	Number	Number	% change	Number	% change	Number	% change
After brain death	3.19	3.15	1.3	3.14	1.7	3.14	1.5
After cardiac death	2.01	2.15	-6.3	1.93	4.1	1.43	40.3
Total	2.81	2.90	-3.0	3.02	-7.0	3.07	-8.5

Note: Transplants after brain death only include those transplants where the donor was from the UK

Organ donation registrations (as at 31 March)

Year	2009	2008		2004		1999	
	Number (millions)	Number (millions)	% change	Number (millions)	% change	Number (millions)	% change
Number registered	16.12	15.14	6.5	11.17	44.3	6.56	145.7

Donation rates and population on Organ Donor Register by UK country

	Deceased donors per million population		Population on Organ Donor Register (millions)	
	2008/09	2007/08	2008/09	2007/08
England	15.3	13.6	13.16	12.45
Scotland	14.1	10.6	1.66	1.54
Wales	13.0	16.7	0.81	0.75
Northern Ireland	12.2	12.8	0.44	0.39
UK	14.9	13.4	16.12	15.14

Note: The location of deceased donors is identified by the location of the donating hospital. The total population on the Organ Donor Register includes a small number of people where their location was not identified

More statistical information is available in the Organ Donation and Transplantation Directorate's annual report, available from NHSBT at www.organdonation.nhs.uk

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