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The newsletter for everyone involved in organ donation and transplantation

Issue 72 Winter 2009

Encouraging response to 'Prove It' campaign

The 'Prove It' campaign was launched across the UK on the 2nd November with national and regional news programmes covering the story.

The campaign launch focused on the gap between people's good intentions and action. The press release highlighted the fact that while 96%¹ of us would accept an organ if we needed one, only 27% of us have joined the NHS Organ Donor Register (ODR).

Media interviews were handled by Lynda Hamlyn, Chris Rudge and Sally Johnson. Donor Transplant Co-ordinators around the UK provided additional support by giving interviews to the regional and local media. Transplant recipients provided the human interest angle for journalists.

Before the launch the a photo opportunity was offered to the media to highlight the fact that at least 33 people who needed a transplant would die in the 11 days up to the launch of the campaign. Two-year old Louisa McGregor-Smith, who received a heart transplant at Freeman Hospital, Newcastle when she was just five months old, was dressed as 'Dorothy' from the Wizard of Oz and gave a heart to 33 'Tin Men'.

The pre-campaign teaser and the launch generated 168 pieces of coverage in the broadcast, print and online media, nationally and regionally. The launch



Prove it campaign gets off to a heart-felt start

was also covered by the trade press and consumer magazines, with further interest still being expressed. The initial response to the campaign has been extremely encouraging. During November, more than 162,000 people visited the organ donation website, of whom over 147,000 were new visitors to the site.

The television advert ran during the highly popular X-Factor on the 8th November, resulting in 5,273 visits to the website between 8-9pm. This was one of a number of advertising slots booked in order to target specific audiences, in this case, families watching television together.

The website has proved to be the most popular registration route so far, with the majority of registrations coming in online.

There were 112,588 completed registrations

during November and although the figures are still going through the validation process, there appears to be a similar conversion rate to other campaigns.

A key component of the campaign has been to enhance NHSBT's presence



on social networking sites, such as Facebook, Twitter, YouTube and Flickr. This has generated considerable online discussion about organ donation in general and the campaign in particular. This activity, which is being monitored throughout the campaign, provides real time reaction to its tone and content. The following comment was posted in the first week of the campaign:

"The new NHSBT campaign came on whilst I was (Cont page 3)

Channel	Completed ODR Registrations November 2009	Completed ODR Registrations November 2008
Website	96,020	22,182
Donor line	5,057	1,513
Text	641	3
Leaflet	10,870	10,397
Total	112,588	34,095

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Copy date for next issue
1 Feb 2010

Please email
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with ideas for submissions

Award winning ICU consultant

A training programme which simulates the care of a patient dying in intensive care, has won top award in the North West NHS Innovation Awards.



Arpan Guha

The course has been developed by intensive care consultant Arpan Guha, who works at the Royal Liverpool and Broadgreen University Hospitals NHS Trust and is a member of NHSBT's Donation Advisory Group.

The course involves simulation of a patient's treatment in intensive care. A team of doctors, nurses, and actors playing the part of relatives are filmed responding to the patient's deterioration. The film is played back to the group for lessons

in how best to discuss organ donation.

Arpan said: "I'm delighted we've won the award because it recognises the importance of improving end of life care and the need to support staff dealing with families.

For doctors and nurses there is little in their formal training which teaches them how to communicate with grieving relatives."

Further information about the course can be obtained from arpan.guha@rlbuht.nhs.uk.

New appointments at ODT



Anthony Clarkson

Anthony Clarkson has been appointed Assistant Director of Organ Donation at NHS Blood and Transplant. This is a new role and will concentrate on managing the Donor Transplant Co-ordinator teams whilst establishing robust frameworks in order to increase organ donor rates. Anthony's previous role was as Head of Clinical development for Tissue



Sue Falvey

Services and Professional Lead for the Eye Retrieval Scheme. He has over ten years experience working in various roles leading to significant changes within tissue donation and redesigning the donation pathway for deceased tissue and eye donors.

Anthony will be taking up his new post later in the year when his priorities will be: to lead, motivate



Dominique Cook

and develop the donor transplant co-ordinator workforce to meet gold standard practice and secure every organ, every time and to support the development of organ donation as usual rather than unusual in every UK hospital. This position is key to meeting our aspiration of increasing organ donation by 73%.

Sue Falvey, formerly Director of Donor Care and Co-ordination,

takes on a new role in January as Head of Nursing Development. This job concentrates on the professional development and training of Donor Transplant Co-ordinators. Sue spent 20 years working as a nurse in organ transplantation at St Mary's Hospital, Paddington and Addenbrooke's and Papworth hospitals in Cambridgeshire. She joined UK Transplant in 1997 as duty office manager and in 2002 took up the position of Director of Donor Care and Co-ordination.

Dominique Cook has been appointed into a new role as the DTC Service Educational Co-ordinator. Her remit is to maintain and organise the current education provided for DTCs, to scope the education and training needs of the DTC workforce and make recommendations for future requirements and provision. Dominique was previously based within the Cardiff DTC team for over six years.

uk news round



Scotland

As winter fast approaches, Scotland continues to make steady progress in implementing the Taskforce recommendations. We now have 20 Clinical Leads for organ donation in post and eight out of eleven NHS Boards have established Donation Committees. These groups have established communication networks for sharing of information and good practice and have both met on two occasions.

The Scottish Government, in line with the strong support which the Cabinet Secretary for Health and Wellbeing has given to the implementation in Scotland of all of the recommendations of the UK Organ Donation Taskforce, has made funding available for a Scottish media and advertising campaign which we expect to run for several weeks from the middle of January 2010. Although the arrangements have not yet been finalised, we expect the campaign will employ the same approach as has proved successful over a number of years: the use of case studies placed in the media by a PR company, run in tandem with the advert itself, with the intention of prompting people to sign up to the NHS Organ Donor Register.

In line with the rest of the UK, the planned extension of the Potential Donor Audit into emergency medicine departments is ongoing. The Emergency Medicine Department at the Southern General Hospital in Glasgow has embraced this with enthusiasm and is working closely with the embedded Donor Transplant Co-ordinator, Deborah Hill and the Clinical Lead for Organ Donation, Dr Catriona McNeill.

Deborah reports that "Through close collaboration between myself, Catriona and the staff in the Emergency Medicine Department, the introduction of the audit has been a smooth process. We have put in place methods of data collection and feedback which accommodates the needs of all concerned. The provision of quantifiable data is something that excites the unit and they feel it will serve to highlight areas of good practice as well as improving potential donor identification".

Pam Niven



Wales

The NHS in Wales has been undergoing a major reorganisation and from 1 October 2009 we now have seven integrated organisations, local health boards, responsible for all healthcare services.

Progress continues to be made in implementing the taskforce recommendations, including appointing Clinical Leads for Organ Donation and establishing Organ Donation Committees.

The Welsh Assembly Government has published the public consultation report on options for changes to organ donation consent, including an opt-out system in October 2009. A copy can be accessed at <http://wales.gov.uk/topics/health/nhswales/majorhealth/organ/?lang=en>. The Minister for Health and Social Services is now considering the next steps.

Caroline Lewis



Northern Ireland

On November 4th, the Northern Ireland Organ Donation Implementation Group held an event to raise awareness of the Organ Donation Taskforce recommendations and the local implications in meeting the challenge of increasing donation rates by 50%.

The event aimed to inform senior professional and managerial staff across the Health and Social Care sector about organ donation. The day got off to a good start with the Minister for Health, Social Services and Public Safety, Mr Michael McGimpsey, providing opening remarks. Dr Eddie Rooney, Chief Executive of the Public

Health Agency reiterated the message that everyone has a role to play in organ donation – both personal and organisational.

Overall this workshop was extremely productive and useful. Not only did it provide local publicity, but it also resulted in a significant number of personal pledges from the delegates involved. Delegates also availed readily of the opportunity to input to the development of a structured approach to increasing donation locally. The outputs from the day are currently being collated and will be circulated to the delegates and will be condensed to form the basis of an action plan for the region over the coming months and years.

On 18 October the local DTC team held a Service of Remembrance and Thanksgiving for Donor Families and Transplant Recipients. Approximately 800 people attended the event which was held in Spires Centre. All who attended seemed to find it meaningful and the exchange of floral tributes between transplant recipients and donor families was once again the highlight of the event.

Four new DTCs have commenced employment during the month of November and recruitment for a further four posts will take place in January 2010.

Siobhán McKelvey

Chiefly



Sally Johnson Director Organ Donation and Transplantation

What a difference a day makes! Usually we get around 500 people signing up to the organ donor register every day using the website or donor line but

on 2 November, the day we launched our first advertising campaign across the UK we saw a massive boost for organ donation with 7,482 people joining the register.

This is the culmination of months of work. We began by commissioning research into why people don't join the organ donor register. We found, as you would expect, a whole spectrum of opinion but a large number of people said they were

ready to join but just didn't get round to it. Others said they were more or less ready to join but needed to discuss the issue with their family first. People told us that we needed to be bolder and make the issue immediate and relevant to them and their family. Many thought that if you were prepared to accept an organ transplant, you should be prepared to donate too. This concept formed the basis for the campaign with 96% of us prepared to accept a transplant if we need one but only 27% signed up to donate after our death.

Campaign launch day was very busy: Lynda Hamlyn could be heard on the today programme on Radio 4 and then after a photocall she toured the TV studios for interviews. Chris Rudge also attended the photocall and then joined living donor Sarah Springett and her partner Paul Shepherd, to whom she gave a kidney, on Woman's Hour. I meanwhile was holed up in a small radio studio talking to 25 different radio stations.

Our adverts will continue to run through November on TV, radio, in the papers and on-line. There will then be a break before a second burst in January and then a third burst in March. Between January and March there will be 20 roadshows across the UK to give the campaign a more local focus and where people will be able to sign up immediately. We have also commissioned a second strand of publicity targeted at black and minority ethnic communities which will also run during the first three months of 2010. If you are planning any campaigns locally please do use the new materials so people see the link with the UK campaign.

It is too early to say how much difference the campaign will make. We aim not only to reach our first target of 20 million people on the organ donor register by the end of 2010 but also to get families talking about organ donation so increasingly people view it as a usual rather than unusual part of life and death.

Encouraging response to 'Prove It' campaign cont.

watching TV the other night. I was totally unprepared for it. As a mother who had to watch my 7 year-old son die awaiting transplant, I thought it was very good. I found it upsetting because I could relate to it, perhaps too much. It may be hard-hitting, but it reflects the reality of the situation and will hopefully

encourage more donors to sign up."

Two further bursts of advertising will run during January and March, supported by additional PR activity.

In the first three months of 2010, a series of roadshows will be held across the UK, which will take the campaign directly to local communities in areas where people

work and shop.

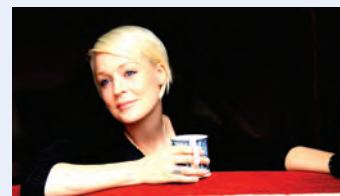
Planning work is also under way to develop the most effective means of engaging with Black and Minority Ethnic communities, under the umbrella of the overarching campaign.

¹ Survey of 1975 people in the UK (YouGov 2009)



Louisa McGregor-Smith and 33 Tin Men in pre-campaign teaser

NHSBT backs organ donation song



Sarah Springett

Living kidney donor, Sarah Springett, has been a major supporter of the campaign to get many more thousands of people to join the NHS Organ Donor Register. The 28-year-old singer-songwriter from Colchester thought of her own personal campaign 'I Hope You Know' after donating one of her own kidneys to her boyfriend, Paul Shepherd, in November 2008. Paul needed the life saving transplant after being diagnosed in 2004 with IgA Nephropathy - a condition where the kidneys become damaged by a protein normally used to fight infection.



Sarah with boyfriend Paul Shepherd

After Sarah had recovered from the operation she focussed on resuming her career as a singer. Sarah's band, The Floe, have followed the national campaign launch with the release of their debut single, also called 'I Hope You Know'. Each single (both physical and digital) will come with an organ donor registration form.

You can join Sarah's campaign by logging on to the 'I Hope You Know' website (www.ihopeyouknow.co.uk). In addition to being able to sign up to the NHS Organ Donor Register, visitors will be able to purchase the 'I Hope You Know' single, with all profits going to The Transplant Trust.

More information

You can join Sarah's campaign by logging on at www.ihopeyouknow.co.uk



Students sign up as lifesavers

This year freshers fairs across England were over-run with 'Hoff' lookalikes as nearly 8,000 students signed up to be lifesavers by becoming blood or organ donors – or both. Many students were keen to show their support by donning masks of the cult Baywatch star, David Hasselhoff.

This was the first time blood and organ donation has been promoted jointly as the 'Lifesaver Roadshow' travelled to 19 universities across England. With the specially produced stand and joint leaflet, the approach was welcomed by the students and NHS Blood and Transplant staff alike.



We can't all be the Hoff, but we can all be lifesavers. Students sign up to be blood and organ donors at Freshers Fairs this Autumn

Local DTCs and blood donor staff working together

The dedicated tour team was enhanced at fairs by the involvement of local blood donor relations staff and donor transplant co-ordinators. Undoubtedly their input not only made an impact on the number of students who signed up but also meant there were specialists on hand to answer detailed questions from students.

The total number of combined signups for the whole tour was an impressive 9,192. The number of blood enrolments was a very encouraging 6,567 – more than 2.5 times more than 2008 figures overall. Although these figures are impressive, it won't be till early in 2010 that the full picture emerges of those who signed up have gone on to donate blood.

Slightly disappointing was the number of students joining the Organ Donor Register, with signups down by an average of 53% on previous years.

The pie chart shows the split of signups into blood only, organ only and joint. The number of students signing up to both was lower than expected. Holly Mason, Lead Blood Donor Relations Manager for the Midlands said 'From the feedback comments, students said this was because joining the Organ Donor Register was a much bigger decision than signing up to give blood. By signing up to give blood they were not committing themselves, but with

organ donation they were.'

To gain more of an insight into why students signed up to one rather than the other or both, the Strategic Marketing team at NHSBT carried out a survey of nearly 150 students at the last five fairs of the tour. The vast majority (94%) said they supported the joint donation approach and 39% said they were already on the ODR, which shows a very encouraging level of support already amongst the student population.

Almost a third of people said they only support one type of donation, that is they only wanted to be either a blood or an organ donor. With a bit more careful targeting we believe these students are potential conversions. Around a sixth of those questioned said it was too time consuming to sign up to both; better leaflet and form design next year

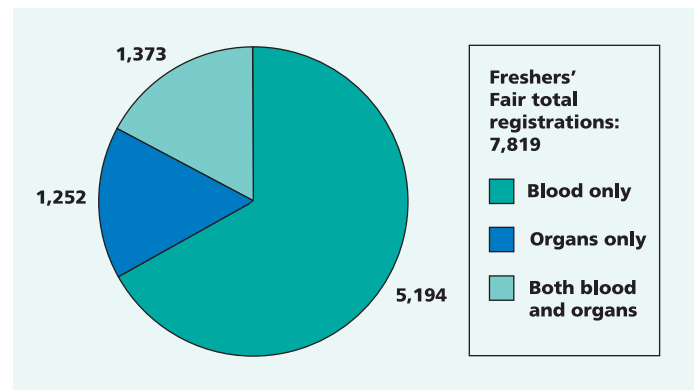
could help convert this group to become joint donors.

The joint stand was definitely a success in terms of meeting students' needs. With an increased level of partnership working between Strategic Marketing and the Blood Marketing and Donor Relations staff, and improvements to the joint form there are encouraging signs that in the right situations the joint donation approach will benefit both blood and organ donation.

Kate Baldwin
Strategic Marketing, NHSBT

More information

To order organ donation campaign posters and leaflets from NHSBT to put up in your Trust visit www.organdonation.nhs.uk



New sign-ups

Patient Organ Advisory Groups

Organ transplantation, as every other activity of the NHS, is focused on the individual patient and the provision of the best possible care within the resources available. It is, therefore, essential that patients,



Professor James Neuberger

who are the focus of the NHS as well as the funders, have a key role in determining health care policies. This is especially important in transplantation. Organ transplants are life saving procedures but as there remain far too few organs available to meet the clinical need, some form of rationing has to occur. Thus, policies on selection (who gets on to the waiting list) and allocation (who gets a donated organ) will have literally life and death consequences for patients.

NHSBT is heavily reliant on the advice of health care professionals in drawing up policies for selection and allocation and the Advisory Groups play a key role in this process. In the past, each Advisory Group had a patient representative. This worked well for some groups but some felt they were unable to represent the views of all patient groups and others felt intimidated by being outnumbered by the professionals, who are usually forthright in their views.

We have therefore changed our approach to patient involvement. We have started, for each of the organs, to hold a meeting with representatives of national and local patient groups which will be attended by myself, as Associate Medical Director, and the Chair of the Advisory Group.

“ The aim is that the meetings will be informal and inclusive and provide an opportunity for patients and their families to comment on and suggest changes to policies...”

The aim is that the meetings will be informal and inclusive and provide an opportunity for patients and their families to comment on and suggest changes to policies, as well to discuss any other aspect of the work done by the groups.

We have held one meeting for the Liver and have planned dates for Kidney and for Heart and Lung, to be held in the New Year. The Liver Meeting was held in London and was attended by over 20 people. It was a very useful first meeting and we have learned a lot which will help us make the next meetings more constructive.

Professor James Neuberger
Associate Medical Director Organ Donation and Transplantation

More information

If you would like to attend contact Kathy.zalewska@nhsbt.nhs.uk

New developments in Statistics and Clinical Audit in NHSBT

The development of an evidence base for the furtherance of organ donation and transplantation, blood and tissue services, haematology and transfusion medicine relies heavily on sound statistical underpinning and clinical audit.

To meet the demand for the design and analysis of quantitative studies in all these areas and to strengthen clinical audit activity, a new Statistics and Clinical Audit service has been established by NHSBT.

Service evaluation and clinical audit can lead to improvements in organ, blood and tissue services. Because much statistical work is focussed on organ donation and transplantation, some examples from this area are given to illustrate the breadth of activity. Opportunities in other areas are then highlighted.

“ Service evaluation and clinical audit can lead to improvements in organ, blood and tissue services. ”

Studies in organ donation and transplantation

The identification of factors that affect waiting time to transplantation, and graft and patient survival time following transplantation, is important for a number of applications. In particular, this information indicates the factors that need to be accounted for in an organ allocation scheme, enables estimates of survival rates to be obtained for patients with particular characteristics, and facilitates the monitoring of centre specific outcomes. For example, an analysis of factors associated with death on the liver transplant list has led to the development of an index of the severity of liver disease in patients registered for a transplant. The index is now being used to ensure that the condition of patients being registered is comparable between the liver transplant centres, so that there is equity of access to transplantation.

Antibody incompatible transplantation

Data associated with the introduction of novel transplant procedures

enables their advantage to be quantified. To this end, a national registry of antibody incompatible kidney transplants has been established to enable outcomes following ABO and HLA incompatible transplantation to be defined, as well as establishing permissive levels of antibody. Initial results have shown that unadjusted three year graft survival rates are similar for both ABO and HLA incompatible transplantation, and are close to the 88% survival rate for deceased donor kidney transplantation. As the size of this patient group increases, more detailed analysis that incorporate risk adjustment will become possible.

Pancreas allocation

Inorganallocation, a national allocation scheme for both pancreas and islets has been developed. Following the identification of key factors associated with outcome, namely waiting time, level of sensitisation, cold ischaemic time and donor body mass index, over 40 different allocation algorithms were compared using a simulation process. A particular scheme has now been agreed with the pancreas transplant community and the IT infrastructure needed for its implementation is under development. The merits of a universal liver allocation scheme based on either clinical need or transplant benefit are now being investigated.

Potential Donor Audit

Much information about the potential for donation in the UK, and statistics such as the proportion of potential donors who actually donate, known as the conversion rate, has been obtained from the Potential Donor Audit (PDA). This study of whether patients who die in intensive care units across the UK become organ donors has shown that there are three obstacles to the supply of deceased donor organs for transplantation. These are the identification of potential donors, referral of potential donors to donor transplant coordinators and obtaining the consent of relatives; for example, the audit has shown that when approached, only 60% of relatives give consent for solid organ donation to proceed. Procedures that are designed to improve these aspects of the donation pathway are now being introduced.

Studies in transfusion medicine, stem cell and tissue transplantation

One of the main drivers for the establishment of NHSBT's Statistics and Clinical Audit service was to provide increased support for observational studies designed for service evaluation in all areas. This has led to our involvement in a number of major projects. These include a multi centre observational study on the use of blood components in paediatric cardiac surgery, a study funded by the National Institute of Health Research on traumatic coagulopathy and massive transfusion, and a study of bleeding tendency in children in Intensive Care Units. An important issue in many of these studies is how the need for blood products, or the incidence of coagulopathy, depends on demographic characteristics, the clinical management of a patient, and other factors, and this in turn requires the development and validation of statistical models.

There is a long history of following up recipients of solid organ and corneal transplants, and the quality and completeness of data in the UK Transplant Registry is of a standard comparable to that of many clinical trials. The need for outcome data following stem cell transplantation, and the transplantation of tissues is now recognised, and we are looking forward to contributing to the development of a process that will enable clinical practice in these areas to be informed by an evidence base built on outcome analyses.

Clinical Audit

Clinical audit is essential for quality improvement in all areas of NHSBT activity and real improvements in service result from aligning clinical audit to the clinical risks associated with the donation and transplantation of blood, tissues and organs. Plans for future audits are likely to be stimulated by the specification of appropriate triggers for an audit, and the audit cycle used to promote quality and clinical effectiveness. New partnerships between clinical audit staff and statisticians will mean that audits are based on sound sampling strategies, with sufficient numbers of individuals to ensure that the results are meaningful. The audit results will then provide a sound basis for subsequent action.

The Care Quality Commission now requires all NHS organisations

to comply with standards for clinical audit. For NHSBT, these include the formulation of an audit programme to facilitate improvements in the service that we provide to both donors and patients. In addition, the establishment of the National Clinical Audit Advisory Group demonstrates an increasing emphasis on the importance of clinical audit within the NHS.

“ One of the main drivers for the establishment of NHSBT's Statistics and Clinical Audit service was to provide increased support for observational studies designed for service evaluation in all areas. This has led to our involvement in a number of major projects. ”

The future

We all welcome the opportunity to collaborate with scientists and clinicians in services related to blood, tissues and organs, who are developing observational studies designed to evaluate service provision, as studies in their own right or as a prelude to a clinical trial. We also encourage early discussion of proposals for clinical audit. More substantive engagement on project work will generally be through funded projects, and we are particularly keen to be involved at an early stage in the development of grant proposals where statistical input is anticipated.

Professor Dave Collett

Associate Director Statistics and Clinical Audit
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More information

This article also appears in *Blood and Transplant Matters*, available on request from carol.griffin@nhsbt.nhs.uk

Quality of life following paediatric cardiothoracic transplantation

Dr Amy McNaughton, Chartered Clinical Psychologist at the Freeman Hospital, Newcastle Upon Tyne looks at the quality of life following heart and lung transplants in children.

The first paediatric cardiac transplant at Freeman Hospital was in 1987 and the first paediatric lung transplant in 1990. Since then there have been over 200 heart or lung transplants. It is now estimated that over 80% of children receiving a solid organ transplant will survive into adolescence and adulthood (Kelly, 2006). Whilst there have been many, significant medical and surgical advances documented during this time, there has been little systematic, rigorous research into the quality of life of children following transplantation.

There are many benefits for children following transplantation: extended life expectancy and the potential to participate in more

activities at school and at home. Children are able to take part in simple childhood pastimes which are often taken for granted. For example: riding a bike with friends, managing full days at school, and taking part in PE lessons. Moreover, it would appear that, overall, developmental and cognitive functioning post transplant is within the normal range for these children (Wray et al, 1992) and therefore participation in such activities is not disadvantaged. Another study (Petroski et al, 2009) showed that, despite serious, late complications, a cohort of adult transplant patients at least ten years out from paediatric cardiac transplantation, reported physical and mental health similar to that of the general population.

The life saving and dramatic changes brought about by a paediatric organ transplant are significant and far-reaching. In the main, children



Dr Amy McNaughton

and families are offered a life-line during an extremely distressing time, by another (the donor) family for whom all hope is gone. This precious gift can bring about immense physical, psychological and social change for the transplanted child and their loved ones. These changes go on throughout the weeks, months and years following transplant surgery and usually result in great joy and increasing quality of life for all involved.

Psychological adjustment

However, whilst a transplanted organ is an amazing gift, a transplant can bring difficulties for some children and families. Uncertainty, loss of role (e.g. student, sportsperson, healthy child), adjustment to new situation, traumatic reactions, difficulties adhering to a lifelong medication regimen, changing appearance with medication, regular hospital visits, changing future and shorter life expectancy are all possible consequences of transplantation which can interrupt a child's social, psychological and physical development and, therefore have a negative impact on quality of life. Children do not exist in isolation; they are part of families, schools and communities and there are changes in quality of life for those in their wider systems, particularly parents and siblings. For example: the potential to get back to a 'normal' family life following a period of critical illness and great uncertainty, and, at times, a new perspective on life.

Not surprisingly most families can benefit from professional assistance in making the tremendous adjustments necessary to cope with life-threatening illness and subsequent post transplant care. Thankfully most families and children make that adjustment and go on to have rewarding and extended lives.

Acknowledgments: The children and families we work with and The Paediatric Cardiothoracic team at Freeman Hospital, in particular, Dr Richard Kirk, Julie Flett, Terry Hewitt and Laura Lane, Angela Nicholson.

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More information

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If you would like to see a copy of our sister publication **Blood and Transplant Matters**, email carol.griffin@nhsbt.nhs.uk

A new era in intestinal transplantation

Dr Girish Gupte,
Consultant Paediatric
Hepatologist at
Birmingham Children's
Hospital looks at the
progress being made
with intestinal
transplantation.

Intestinal transplantation is being offered for children and adults with life threatening complications related to intestinal failure defined as: critical reduction of functional gut mass below the minimal amount necessary for adequate digestion and absorption to satisfy body nutrient and fluid requirements for maintenance in adults and children.

Most of the children and adults with intestinal failure (Table 1) can survive on long term home parenteral nutrition (PN). There is no doubt that

home PN is an effective treatment that has improved survival of adults and children with irreversible intestinal failure in the last three decades. However, some develop severe complications such as liver disease, impaired venous access and recurrent life threatening complications and would benefit from timely referral for intestinal transplantation.

The current criteria for intestinal transplantation are as outlined in Table 2. There are certain exclusion criteria for intestinal transplantation which are outlined in Table 3. The type of transplant is decided by the severity of the liver disease. In children and adults with mild or no liver disease, isolated intestinal transplantation is an option while in children and adults with moderate to severe liver disease, combined liver and bowel transplantation can be performed.

The operation

The operation can last from seven to 13 hours depending on the complexity of the case. The median hospital stay following an intestinal transplant may vary from one to three months depending on the complications in the post-transplant period. In the majority of children and adults, PN is discontinued within a few weeks after intestinal transplantation and they are discharged home on a combination of tube feeds and normal diet.

In the last decade, increasing numbers of intestinal transplantation are being carried out in 71 centres across the world. To date more than 2000 intestinal transplants have been performed. The results of small bowel transplantation have improved dramatically in recent years with an 90% one year survival reported from the intestinal transplant registry (www.intestinaltransplantregistry.org) and some individual centres around the world reporting similar figures for three year survival.

The focus of the intestinal transplant community has shifted from short term survival to long-term survival with issues related to quality of life. Quality of life is a difficult domain to assess as it is a broad-ranging concept affected in a complex way by health, psychological state and social status and can vary from individual to individual. The lack of a standardised quality of life instrument means that it is difficult to compare the quality of life reported from different studies. There have been few studies made in adults and children following intestinal transplantation and there is a need for a larger multicenter study.

Survival rates

O'Keefe⁵ reported on quality of life in a cohort of 46 adult patients 12 to 36 months after intestinal transplant. This group of adult patients were found to have significant improvements in 13 out of 26 domains assessed after transplant. There have been few studies comparing quality of life of home PN and intestinal transplant recipients. Pironi² compared quality of life in adults on home PN and following successful intestinal transplantation. The subjective health feeling in adults following intestinal transplantation was better than in adults on home PN, whereas vitality and mental domains were comparable in intestinal transplant and home PN adults.

Impact on parents

Children's ill health can have an

adverse impact on quality of life of the parents. Sudan³ reported on quality of life in 10 to 16 year old small bowel transplant recipients. The recipients rated their quality of life as equivalent to healthy children of the same age, although their parents remained more anxious than the parents of healthy children.

Our group (unpublished work) has compared the quality of life in parents of children on home PN or pre-intestinal transplantation, and to examine the changes in parental quality of life in the first year post intestinal transplantation. Our results showed that both home parenteral nutrition and pre-intestinal transplantation had significant impact on parental mental health, with all areas of mental health affected.

Parents of children on home PN reported worse mental health in all domains than parents of children awaiting intestinal transplantation. Some parents with children on home PN even reported severe depression. It was reassuring that intestinal transplantation had a positive impact on parental mental health, with all domains improving with time post transplantation. Impact on parental emotions also improved over time following intestinal transplantation.

In summary, not only are the results of intestinal transplantation improving over the last few years, but children and adults following intestinal transplantation can expect to live longer and lead a good quality of life.

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More information

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Surgical

- **Surgical SB secondary to neonatal disease:**
 - Necrotising enterocolitis
 - Volvulus
 - Gastroschisis,
 - Intestinal atresia.
- **Surgical SB secondary to**
 - trauma
 - mesenteric vessels disease (ischaemia, volvulus),
 - extensive IBD or radiation enteritis
 - Gardner's syndrome and desmoid

Non-surgical

- **Primary enterocyte disease:**
 - Microvillous inclusion disease
 - Tufting enteropathy
 - Protracted diarrhea
- **Malabsorption secondary to**
 - Crohn's disease
 - radiation enteritis
 - lymphangectasia
- **Gut motility disorders:**
 - Chronic primary pseudo-obstruction
 - Hirschprung's disease

Table 1 : The common causes of Intestinal Failure in paediatrics and adults

- **Irreversible intestinal failure with major complications**
 - Recurrent or life threatening sepsis
 - Loss of 50% or more central venous access sites
 - Recurrent and intractable fluid balance issues
 - Liver disease with portal hypertension

Table 2: International criteria for intestinal transplantation

- | | |
|--|---|
| <ul style="list-style-type: none"> ■ Absolute <ul style="list-style-type: none"> • Profound or progressive neurological dysfunction • Non-correctable disease in organs outside GI tract • Active systemic sepsis • Malignancy • Psychosocial problems – severe and irreconcilable | <ul style="list-style-type: none"> ■ Relative <ul style="list-style-type: none"> • ITU care • Immunodeficiency • Drug dependency • Loss of conventional venous access • Neoplasia benign or of uncertain prognosis • (<i>per se</i> age is not a contraindication) |
|--|---|

Table 3 : Contra-indications for intestinal transplantation

Launching a professional development programme for clinical leads

An exclusively designed professional development programme intended to introduce UK wide Clinical Leads and Non-Clinical Champions to the complexities of organ donation will be launched on 1st February 2010. The programme has been designed by NHSBT in association with Deloitte, the professional services firm. Deloitte have expertise in the design and delivery of leadership programmes and organisational change and extensive experience of working with leaders in the health sector.

A range of national and regional events are planned throughout 2010 and will meet a wide range of learning needs. Delivery will include clinical master classes with real life scenarios focused on strategic improvement areas. 'Pod casts,' and an on-line self assessment tool together with regional peer consulting groups to support best practice learning, however remote the participants happen to be.



Bruce Keogh

“ This exciting, innovative programme will not only give you skills to increase organ donation in your hospital but will support leadership to the benefit of the whole NHS. ”

Bruce Keogh

The programme has gained the support of many professional bodies including:

- The Department of Health
- The NHSBT Donation Advisory Group
- The Royal College of Anaesthetists (including lay individuals)
- The Intensive Care Society
- The College of Emergency Medicine
- The Royal College of Paediatrics and Child Health
- The British Association of Critical Care Nurses

The Professional Development Programme will:

- Build participants knowledge, skills and experience and enable them to facilitate behavioural and attitudinal change including:
 - 11 clinical expert areas
 - Initiating change and developing change management strategies
 - Overcoming resistance and behavioural analysis
 - Dealing with stakeholders
 - Leading and managing change
 - Changing organisational culture
 - Business planning cycle
- Deliver a sense of community and networks and encourage sharing of ideas and developing of best practice
- Be aligned to the needs of the organisation and its stakeholders
- Be based on expert input - from NHSBT and NHS organisations (Clinical / Non-Clinical Donation Champion and Donor Transplant Co-ordinators and clinical Subject Matter Experts).
- Facilitate events offering access to leading thinkers to inspire and challenge participants.
- Be based on real issues and challenges that matter to Clinical and Non-Clinical Leaders and their organisations, focusing on benefits aligned to improving Organ Donation
- Be supported by robust governance - A group comprising NHSBT, Deloitte, NHS organisations and key participants will steer the programme, allowing clear accountability and measurable, aligned results
- Focus on outcomes – increasing Organ Donation whilst respecting the need of the patient, the family and society
- Focus on collaboration between Clinical Leads, Non-Clinical Champions and Donor Transplant

Co-ordinators

- Enable individuals to undertake self assessment to understand priority development areas to focus on
- Integrate seamlessly with any clinical education tool/programme developed by DH
- Meet “standards” for a clinical education programme
- Minimise time away from patients for clinicians
- Utilise blended and tailored delivery methods; including discussion, debate and reflection
- Support regular communication of programme progress - success stories for the programme
- Provide a sustainable element to the programme and support continuous improvement

Boost knowledge levels

Curriculum materials are currently being developed by Clinical Leads with specific expertise (Subject Matter Experts). Topic materials are designed to increase both knowledge and confidence of Clinical Leads and Non-Clinical Donation Champions to identify, lead, initiate and deliver changes within their organisations, including the start up of new donation programmes from scratch for example, donation in emergency medicine or initiating a new non-heartbeating donation programme.

The programme will boost the Clinical Leads' level of clinical knowledge, expertise and confidence around a core curriculum of donation and transplantation subjects to maximise their performance within their leadership roles. It will also identify best practice for donation, retrieval and transplantation and maintain awareness of emerging practice and trends from other legal, ethical and professional bodies.

Clinical topics to be covered include:

- Law and ethics
- Referral, consent and authorisation
- Donor management, physiology and assessment
- Non-heartbeating donation
- Diagnosing brain stem death
- Emergency medicine donation
- Paediatric organ donation
- Tissue donation
- Eye donation

In addition to the clinical components of the course a range of senior



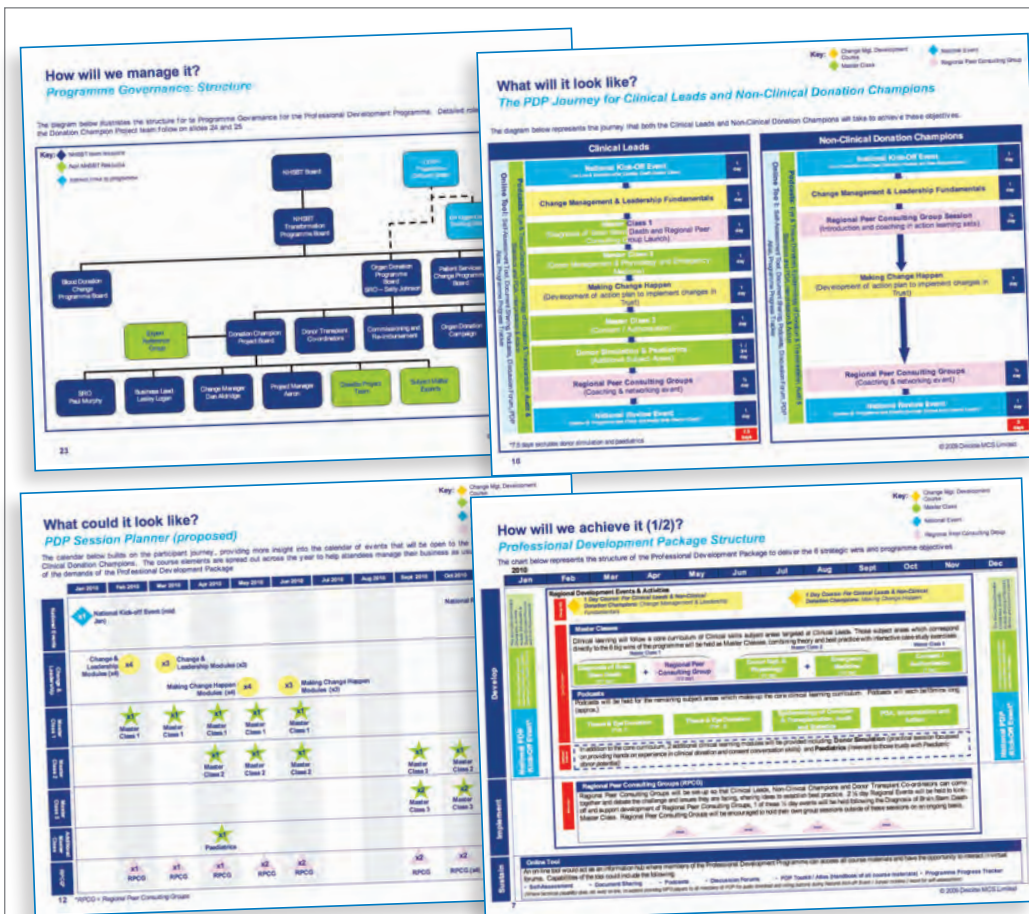
Paul Murphy

“ For people working in this field, this programme offers a great introduction into the many different skills required and will give them a real understanding of how organ donation can be improved. We are delighted to be working with Deloitte on this project and anticipate it being a very lively and popular course. ”

Paul Murphy

management consultants and facilitators drawn from Deloitte will be designing and leading courses to enable Clinical Leads and Non-Clinical Donation Champions to influence and manage behaviours and beliefs of colleagues, as well as overcoming barriers to change.

Attention will also be given to develop Clinical Leads' confidence and skills to address and proactively manage local, regional and national press enquiries and to publicly



The new professional development programme is planned out in great detail

promote local initiatives is another component of the course.

Map of Medicine

Another strand to the programme will be to develop care pathways of best practice in donation. This work will be undertaken by Subject Matter Experts in conjunction with Map of Medicine a web based application designed to define standards of best practice along a clinical pathway.

Versions of these pathways will be freely available on the web for anyone to see in England and Wales and a solution is being sought for Scotland and Northern Ireland.

Regions will have localised versions and be able to personalise content.

Paul Murphy, National Clinical Lead, who is overseeing the project said "For people working in this field, this programme offers a great introduction into the many different skills required and will give them a real understanding of how organ donation can be improved. We are delighted to be working with Deloitte on this project and anticipate it being a very lively and popular course."

Lesley Logan, Business Lead for the project said: "Organ donation doesn't happen by accident, even

the most naturally talented people need proper, high quality training in order for them to realise their full potential. NHSBT places a high priority on training and we're delighted to be involved in this joint venture with Deloitte. We hope that this programme will pave the way for other training and educational partnerships."

Sir Bruce Keogh, NHS Medical Director says "This exciting, innovative programme will not only give you skills to increase organ donation in your hospital but will support leadership to the benefit of the whole NHS'.

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Lesley Logan



Lesley Logan

Ocular Tissue Advisory Group

OTAG met on 1 July 2009

■ The bone and tissue sub-group of SaBTO have reviewed the issue of potential donors with a history of blood transfusion and accepted that eye donors with a history of blood transfusion should continue to not be excluded from eye donation. This matter will be kept under review.

■ Work is ongoing around financial disincentives to trusts in relation to eye donation and retrieval. If co-ordinators wish to be trained in eye retrieval then NHSBT will support this request but there is no absolute requirement for them to do so as part of their role.

■ Work is still ongoing into working out the best method of capturing information on what techniques surgeons are using to insert the graft for endothelial keratoplasty.

■ Work is ongoing to put in place a mechanism for central serology testing. Provision of funding has been agreed with NHSBT. Christmas transport issues have been resolved by local storage of blood until transport is available.

■ A workshop has been held looking at different models for setting the new HTA licence fees. A consultation paper will be produced with a different model for fixing fees.

■ Amendments have been proposed to the transplant record and follow-up forms and these changes will be progressed. Ten-year follow up forms have been piloted in certain centres and will be sent out on a monthly basis to collect ten-year data. If the data is available a long term project will be defined.

■ A protocol is to be drafted for a review of outcomes of transplants for patients who have undergone both a corneal and a solid organ transplant. Interested parties in other countries are to be contacted to ask if they would like to participate in this project.

■ The outcome of paediatric corneal transplants is also being audited.

■ Centre specific reports are to be produced to bring OTAG in line with the solid organ advisory groups. These would be in the form of funnel plots on corneal transplant outcomes for centres. The outcomes would be for first transplant for keratoconus with variables for penetrating keratoplasty and deep anterior lamellar keratoplasty and outcomes for Fuchs Dystrophy with variables of penetrating keratoplasty and endothelial keratoplasty.

■ The number of corneas issued and not used is not reducing and it was suggested that these should be offered to those surgeons who are struggling to obtain corneas via the fax system.

■ Compared with the previous financial year, there was an increase in the number

of eye donors from solid organ donors from 200 to 249. There has also been an increase from 24 to 60 in the number of eye donors from heartbeating and non-heartbeating donors where solid organs were not donated.

- 88% of corneas retrieved by Moorfields and 63% of corneas retrieved by East Grinstead are kept locally and not sent to a CTS eye bank for national allocation. It was, however, acknowledged that the waiting time for patients at Moorfields, along with allocation policies were similar to that of other major centres. The allocation policy for solid organ donation involves HLA matching so those patients who require HLA matching are significantly disadvantaged as they don't have access to the full donor pool of eyes. It was felt to be inappropriate for a patient to have increased access to a corneal transplant from locally retrieved tissue. It was suggested that eyes from solid organ donors, and which are therefore HLA matched, be exchanged with the CTS eye banks to ensure that all patients have access to eyes from HLA matched donors. There were concerns that these centres would then incur a financial disadvantage from this arrangement. Before a decision is made, further information is needed on corneas required and issued, and allocation policies from non-CTS eye banks.

- A proposal was endorsed for the prioritisation of eye retrieval as soon as possible after post-mortem in order to maintain the quality and safety of ocular tissue for transplantation. Unnecessary delays in retrieval should be avoided and, in particular, eyes from solid organ donors should be removed in theatre, either before, during or following solid organ retrieval.

- Following investigation into the requirements of the EU Directive on Tissue Donation and enquires with the Human Tissue Authority for their view it was confirmed that NHSBT will not be exempt from implementing consent arrangements in ocular transplant centres. There is an expectation, therefore, that NHSBT will continue to make progress in the area of consent with all centres during the next year. Members repeated their concerns that the requirement to obtain patients consent for use of their information would affect the legal requirement on centres to capture serious adverse event reporting. However, a pilot study will be established to take this forward. If appropriate, evidence from the pilot will be presented to the National Information Governance Board to support members' concerns.

- From mid-January to the end of April the demand for corneas averaged 200 requests per calendar month which were successful and around 35 – 40 that were unsuccessful (although some of these may have gone on to have a graft

in the following week or weeks). Work is underway to access details on the number of patients waiting for a corneal transplant (to include scleral graft or corneas for glaucoma procedures) in order to estimate the demand for corneas for NHS entitled patients.

- Some surgeons have reported difficulties with the fax ordering procedure for corneas via the ODT Duty Office and of increases in the waiting time for surgery. The Duty Office is to investigate ways of monitoring the allocation of corneas by surgeon, centre and region.

- A proposal to widen the remit of OTAG to include two further ophthalmic products, amnion and autologous serum eye drops (ASE) was put forward. This would present a cohesive service to the users of NHSBT's ophthalmic tissue grafts, products and service. However, queries were raised around the process for monitoring outcomes of users of these products and the follow-up arrangements, which are currently not tracked. This may have significant impact on IT resourcing if required. The proposal was agreed in principle but further detail is required on the implications of such a proposal and the numbers involved. The question of the inclusion of plasminogen eye drops for ligneous conjunctivitis was also raised.

- One of the remits of OTAG is to maintain the standards of eye donation and transplantation which includes donor selection policies. It was agreed to support formalisation of the process of eye donor selection criteria via the Standing Advisory Committees (SAC), such as that for Tissues (SAC-T) to the Joint UK Blood Transfusion Services and National Institute for Biological Standards and Control Professional Advisory Committee (JPAC) with additional expert advice on eye conditions to OTAG from the Ocular Tissue Transplant Standards Group of the Royal College of Ophthalmologists (OTTSG) and other groups. Issues regarding selection criteria would be taken via OTAG to the SAC and JPAC.

- The standard operating procedure for reporting of serious adverse events was established. The outcome of serious adverse events reporting (SAER) from Moorfields will be provided to the OTAG audit group monitoring SAER.

- A draft protocol categorising adverse events & reactions from donation to transplantation was supported and commended. This would be subject to further review and then re-circulated.

- Advice and procedures for dealing with issues of retrieval involving junior doctors will be sought from OTTSG and the Professionals Standards group as necessary.

- Eye retrieval boxes should contain verification of document version and expiry date. This will be followed up with the company supplying the boxes

and the respective hospitals. Centres carrying out eye retrieval should check the boxes for expiry dates and report any issue relating to this.

- The following items were those raised at OTTSG:

- An update was given on the preparation of dissected ocular tissue by the eye banks. Two automated keratomes will be evaluated at the next eye bank meeting.

- There is currently no known method of identifying eyes that have undergone laser refractive surgery. As the numbers are thought to be low it was decided to postpone this discussion. In the meantime, donors with a history of laser surgery will still be excluded. Eyes from these donors may be able to be used for DSEK but no final decision has yet been reached on this proposal. This will be discussed at the next meeting of OTAG.
- On behalf of OTTSG and OTAG the College newsletter included a reminder highlighting the need to return forms to ODT.

- A Group 2 paediatric patient visiting the UK for a medical assessment suffered a spontaneous rupture of the cornea. The Eye Bank was unable to supply any material for this case as Department of Health regulations state that if patients come to the UK for the purpose of obtaining health treatment they must be prioritised below Group 1 patients. In this case tissue was obtained from the EU for the patient but the question was raised as to whether other options would have been available. A clear clinical need was recognised and clarification will be sought on whether corneas are classed as tissues and are therefore not subject to Group 1/2 definition.

Cardiothoracic Advisory Group

CTAG met on 23 September 2009

- The 18-month fellowship in cardiothoracic transplantation at Papworth Hospital has now been filled and the second round of appointments is ongoing for the second fellowship to be based at The Freeman Hospital, Newcastle. Additionally, bids have been submitted to NCG and DH for funding to continue with the programme. Once information on 2011 funding is available then the process to accredit a training programme with the SAC can be progressed.

- The first issue of the hospital trust reports from the potential donor audit were distributed to centres in August to benchmark this against national data. The revised Potential Donor Audit (PDA) is expected to go live after testing on 1 October 2009, which will ensure the provision of timely data to centres. CTAG members requested to be able to see data on individual hospitals.

- The current offering principles for lungs are currently under review.

- Following the independent report on the allocation of organs to non-UK EU residents the DH implementation group has met and will be submitting recommendations to Ministers. At the present time the status quo remains, with no change to the current practice with regard to EU or Group 2 patients.

- As part of the changes to Advisory Group arrangements, instead of having patient representation on the membership of each advisory group an annual meeting will be held with a selection of representatives from patient support groups for each organ. It is hoped to arrange a meeting with the cardiothoracic patient support groups in January 2010.

- To provide for consistency of terminology the databases currently hosted by NHSBT are now referred to as the UK Transplant Registry rather than the National Transplant Database. This will not affect the way in which the data is collected.

- Mrs Rachel Johnson has been appointed to the new post of Head of Organ Donation and Transplantation Studies, with responsibility for the co-ordination of the work allied to the ODT Directorate of NHSBT.

- A new forms development IT infrastructure is being developed as a joint project between NHSBT and consultancy firm Sapient. Four cardiothoracic registration forms are being developed using this new infrastructure.

- In relation to the national heart sharing scheme for sensitised patients, concern was expressed regarding the variation in practice between laboratories. A BSHI ABO special interest group will be meeting shortly focusing on antibody definition of matchability. CTAG concerns will be fed back to BSHI with a request for harmonisation in the reporting for cardiothoracic allografts.

- NHSBT have agreed to support a working group between NHSBT and the British Society for Heart Failure to work on developing referral, selection and allocation criteria for heart transplantation. It is intended that these will eventually be incorporated into PCT and national guidelines. Liaison is also taking place with cardiology groups to incorporate these into the cardiology curriculum.

- Clear guidelines will be developed following a review of internal centre allocation criteria for heart and lung transplantation.

- The audit fields for all potential transplant referrals will be developed by the UKCTA-NHSBT project group and incorporated into the NHSBT datasets. CTAG will consider where this sits in the IT priorities of NHSBT. In terms of IT priorities this piece of work was

prioritised behind the transplant record form and follow-up forms.

■ A small working group will be convened to review the International Society for Heart and Lung Transplantation (ISHLT) guidelines for referral for lung transplantation and produce a strategy for their wider dissemination within the UK. This working group will also review listing criteria and referral criteria for lung transplantation.

■ At present any reviewed allocation system will retain zonal primacy for non-urgent allocation until more information is available. The principle of regional zones will be based on geographical proximity therefore the existing primacy zones should not change ie 1st option – local centre; 2nd option – accepting centre (if able to retrieve in time); 3rd option – next closest local centre. A further review, once robust data is available on selection criteria and referral patterns will be considered once data is available in two years. The issue of time allocation for donor management and the need to make provision for how this care is provided is being considered by NHSBT at the present time. Until a decision is made on which option to take forward it is unlikely that any training in donor management will happen until 2010/11. Members expressed concern at these delays and suggested that NHSBT should consider ways of supporting centres in funding local solutions in the interim.

■ CTAG endorsed a recommendation that the differential organ donation rates, centre attendance and organ yield by retrieval zone should be further explored by a UKCTA-NHSBT project group. Reasons for low donation, attendance and retrieval rates should be defined if possible to allow corrective action to be taken.

■ CTAG endorsed a proposal to move towards more comprehensive donor assessment systems. The UKCTA-NHSBT project group and the two working groups for heart and lung allocation will be asked to consider how to incentivise and reward good retrieval practise and high yields.

■ CTAG endorsed a strategy that enables greater donor assessment towards heart and lung donation and a system that re-offers once assessment (but not management) is complete.

■ The payback scheme under its current

rules will be continued subject to better information on referral, selection and retrieval.

■ A short term working group will be established to review options for organ allocation, including the current system, systems used elsewhere internationally, and systems used for other solid organs.

■ Arising from concerns raised previously regarding hearts from 'large' adult donors being transplanted into paediatric patients, some proposed rules regarding size matching for non-urgent paediatric patients were submitted for consideration. Following simulation the scheme proposed would affect 9% of all paediatric heart transplants over a recent three year period and would protect eight large adult donor hearts from being used in much smaller paediatric patients. Further work on this proposal is required to fine-tune the detail and a revised proposal will be produced.

■ With regard to the issue of equity of access between the two paediatric centres, Newcastle will retain its access to zonal donors for paediatric patients rather than moving to a preferential offering system on a rotational basis with Great Ormond Street.

■ In July NHSBT received notification from Swisstransplant about the introduction of a new European Children's Heart List (ECHL) for all patients up to 12 years of age awaiting heart transplant. Details of the list were sent to Great Ormond Street Hospital and The Freeman Hospital, Newcastle, following which both centres have expressed an interest in registering their patients on the list. Only national organ allocation organisations will have access to the list meaning that NHSBT would be responsible for registering patients in the UK. Work is ongoing to resolve data security concerns in terms of UK requirements.

■ An extension to the payback scheme was implemented on 16 January 2009, such that those centres which export a heart for use in an urgent patient are promoted to the top of the out-of-zone offering sequence and remain there until they have received a heart for a non-urgent patient from outside their zone, when they are then demoted. This extension to the scheme is subject to specific promotion and demotion criteria. The extended scheme will

continue to operate for a further six months and will be reviewed at the next CTAG meeting.

■ Proposed inclusion/exclusion criteria for listing paediatric patients on the urgent heart scheme were agreed at the March 2009 CTAG meeting. The inclusion criteria, incorporating changes agreed by the two paediatric centres, were split into categories that broadly mirror those used for adult urgent patients. The new codes will be circulated to the paediatric centres for use from 1 October 2009.

■ The views of CTAG were sought by the Health Commission for Wales on the principle of undertaking desensitisation before cardiac transplantation for highly sensitised heart patients and on the ethical issues of the duration of desensitisation. Below is a summary of CTAG's response:

- CTAG is not the responsible body for determining the appropriateness of individual patient therapies, nor does it have commissioning within its terms of reference; the infrastructure to support detailed literature reviews or the skills to assess cost effectiveness.
- The decision to use a desensitisation procedure rests with the individual centre and is subject to its own clinical governance procedures.
- In view of the uncertainty about the clinical outcome that can be achieved, the centre should seek a suitable donor from its own zone or through the standard non-urgent national offering sequence. The question of whether desensitised patients should be admitted onto the yet to be implemented sensitised patient scheme will need further debate at CTAG and expert guidance.

■ In the absence of a funded national study, the responsibility for funding the procedure lies primarily with the individual centre and its commissioners.

■ While a centre may request additional funding for such a procedure, the limited evidence on clinical effectiveness and lack of evidence of cost effectiveness would mean that such a request would be on a 'compassionate use' basis. A situation in which funding were diverted in a way that would disenfranchise patients otherwise suitable for transplantation could not be supported.

■ It is desirable that commissioners should either develop a pilot study

of desensitisation or obtain a formal review of the current evidence at the earliest practicable opportunity.

■ Currently there is no national sharing scheme for lungs and there appears to be no universal approach to desensitisation. There is a need to review policy within different centres and to produce allocation guidance on sensitised patients listed for lung transplantation. This work will be incorporated within the remit of the working group reviewing listing criteria and referral criteria for lung transplantation.

■ The policy on when a paediatric donor should be attended by either an adult cardiothoracic retrieval team or a specific paediatric team was submitted to CTAG for clarification. Newcastle is currently the only centre providing a service for both adult and paediatric donors; whilst Papworth, Harefield, Birmingham, Glasgow and Manchester each provide teams based upon adult heart and lung transplant programmes; and Great Ormond Street field a 'small paediatric' team on an ad-hoc basis when necessary. In view of the new retrieval arrangements a cut-off point of 11 years or 30kg in terms of donor size was agreed above which the adult team can provide a competent service.

■ No revisions were proposed to the National Standards on Documentation for Cardiothoracic Transplant Patients. This document will next be reviewed in September 2011.

■ The review of the National Protocol for Assessment of Cardiothoracic Transplant Patients is to be postponed as this will fall within the remit of the working group on referral and listing for heart transplantation. In addition a review and debate on national selection criteria will need to be carried out once 1 year's data has accrued from the new registration forms to be introduced shortly.

■ Proposed revisions to the Donor Retrieval Process for Heart and Lungs were requested. At some time in the future this document may need to be incorporated into a national donor management and retrieval document.

■ CTAG supported a proposal from Papworth for a combined lung/liver transplant programme between Papworth and Addenbrooke's. Several centres are currently considering this type of combined programme.

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