

Ethnicity and Renal Failure:

Disparity or Diversity?

A National Symposium at the British Library May 9th 2003

The UK demand for renal replacement therapy is on the increase and in recent years some areas have seen a three to five fold rise in renal failure amongst Asian and African Caribbean populations compared to Caucasians (Lightstone 2002, Roderick 2002). When these stark statistics are set alongside the geographical inequalities in access to health care, the outcome is a disproportionate representation of minority groups on dialysis and those waiting on transplant lists. As a result, the renal community is well aware of the challenges involved in reaching out to and caring for those from minority groups, but the question remains – is the renal community doing all it can to deliver a fair and equitable service?

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On May 9th 2003, South West Thames Renal & Transplantation Unit and South West Thames Institute for Renal Research hosted the first national symposium 'Ethnicity & Renal Failure: Disparity or Diversity?' at the British Library. The symposium outlined the current epidemiological data on ethnicity, identified causal factors and presented innovative UK and American initiatives designed to reach and treat 'at risk' groups. The aim of the symposium was to raise the profile of the Ethnicity and Diversity in Renal Failure and to promote the concept of inclusive and networked care as a way to tackle primary prevention, organ donation, health planning and health provision.

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We were delighted to have David Lammy MP, Parliamentary Under Secretary for Health to give the opening address and he very clearly emphasised the need to address the advancing challenge of the increased risk of renal disease in minority ethnic groups. Senior figures from United Kingdom Transplant, the British Renal Society, the National Kidney Research Fund and a range of patient and community groups also gave their support to the symposium by attending the day and contributing to the lively discussion.

All of the speakers kindly agreed to have their presentations published in this document and I know that these papers will provide an excellent resource for all members of the renal community in the planning of future health care initiatives.

Sue Woodcock RGN, BSc (Hons), MA, PGCert.

Renal Education Lead at South West Thames Renal & Transplantation Unit.
Event and Programme Organiser.

**Dr David Newman BSc,
MSc, PhD, MCB,
FRCPath**

16th May 1959
– 31st March 2003.

The symposium and these proceedings are dedicated to the life and work of Dr David Newman BSc, MSc, PhD, MCB, MFRCPath. A well loved and respected friend, colleague and scientist. David made an immeasurable contribution to renal medicine including helping to develop the Renal National Service Framework, the Health Technology Assessment programme and the Renal Registry. He will be missed.

People will make the difference, people will narrow the gap between the inner city and Surrey and Berkshire, people will get into the communities and understand the differences leading to disparity in health care.

Prevention is Better than Cure



**David Lammy MP, Parliamentary
Under Secretary of State for Health,**

I am delighted to be able to discuss the challenges we face in tackling the inequalities in renal and diabetic services for those who access the services on a daily basis, as well as clinicians who want to provide high quality services for their patients.

We all know that black and minority ethnic groups experience significant inequality in health outcomes. For example:

- Death rates from coronary heart disease among first generation South Asians aged 20 to 69 are about 50% higher than the national average
- The death rate from strokes among those aged 20 to 69 years and born in the Caribbean is more than 50% higher than the England and Wales average
- Perinatal mortality among Pakistani born mothers is nearly twice the UK national average
- Schizophrenia is three to six times higher among African-Caribbean groups than in the white population
- Women born in India and East Africa have a 40% higher suicide rate than those born in England and Wales.

Current Initiatives and Policy

It is a good time for the NHS. There is much that is good about our renal services. I can think of no other field where the effectiveness of a medical intervention and the commitment of staff and patients have been more apparent than in kidney transplantation or kidney dialysis. The results have been dramatic, extending the lives of thousands of people every year, practically doubling the number of dialysis patients over the last ten years.

The NHS Plan, published in July 2000, recognised that we now live in a diverse, multicultural society, and that, as a result, the NHS must respond to the different needs of different populations. To tackle health inequalities in disadvantaged groups and areas, the plan made reducing inequalities a key criterion for allocating NHS resources. For example, that the NHS must address local inequalities such as access to services for black and minority communities and include a commitment to providing free and nationally available translation and interpretation services from every NHS premises through NHS Direct.

Its also true to say the adage 'prevention is better than cure' comes to mind to describe the Government's programme of National Service Frameworks. The Coronary Heart Disease NSF in March 2000, the Older People's NSF and the Diabetes NSF standards and delivery strategy are important precursors to the Renal NSF and will achieve much to prevent and delay the progression of renal disease.

National Service Frameworks are one element of the government's overall programme of modernisation. They are designed to improve health and social well-being by setting standards for all aspects of prevention, through diagnosis to treatment, to:

- Provide services to more people, more quickly and to a higher standard
- Improve the patient experience
- Reduce variations in care across the country
- Increase compliance with evidence based practice
- Reduce inequalities, by ensuring that services are accessible to everyone, irrespective of their age, gender, race or culture.

In addition, the Government has been involved in and supported many different projects to ensure greater awareness and to strategically plan for culturally appropriate renal services. Looking at the programme for today I recognise the projects such as A better life(ABLE) awareness and community education campaign and Dr. Paul Roderick's research into ethnicity and renal failure.

Achieving sustainable improvements in health and services for black and minority ethnic people is an integral and vital aspect of our programme of investment and reform.

Clinicians, managers and patients recognise the building blocks of national service frameworks as ways to improve standards of care. I would like to talk about the challenge facing the NHS to ensure that modern health care is appropriate to the whole population. No one should be in any doubt that we are determined to ensure that services are as good for minority ethnic communities as they are for anyone else in our society.

Future Initiatives

The Government is committed to transforming the health and social care system so that it produces faster, fairer services that deliver better health and social care and tackle inequalities. Achieving sustainable improvements in health and services for black and minority ethnic people is an integral and vital aspect of our programme of investment and reform. Our strategy to tackle health inequalities aims to narrow the health gap in health outcomes across a range of dimensions, including between different black and minority ethnic groups and the population as a whole, across geographical areas, and across socio-economic groups.

Black and Asian people living in this country are about three to five times more likely to develop renal failure largely due to the high rates of diabetes and high blood pressure amongst these communities. Inevitably this impacts on the demand for renal replacement therapy and transplantation in areas of the country that have higher ethnic minority populations. These statistics paint a bleak picture and it is a salutary reminder of the scale of the health challenge. So I welcome this conference in tackling these important issues as they affect people with kidney disease.

The Government shares your concerns about the lack of organs for transplantation in both the Asian and Black communities. That is why we launched the South Asian campaign in February 1999 and the Black campaign in March 2002, to raise awareness and recruit more potential donors from these communities. In February this year we changed the focus of the South Asian Organ Donor campaign from awareness raising to encouraging more Asians to join the NHS Organ Donor Register. Last year UK Transplant celebrated its 10 millionth donor on the register, although it is difficult to say how many of these are from an ethnic background. It is clear that more work still has to be done and central to achieving this are increased levels of health education and awareness of the specific problems within this population. This is a challenge for all communities and we welcome the support of religious leaders of all denominations who have publicly stated that donation is something that they advocate.

Prevention

The Government recognises the need to deliver effective health care to minority ethnic groups. So to me, it is very encouraging that whenever we are thinking about better renal services, whether it is prevention, diagnosis or treatment, we are thinking about black and Asian people who certainly should get the benefit from better, more accessible services, with the emphasis on prevention.

Delegates continue to discuss the issues over coffee



Meeting the Challenge of Prevention



**The multiplicity of ethnic medicine.
Dr Salman Rawaf
Director of Public Health
Wandsworth Primary Care Trust**

There are different disease patterns in different ethnic groups that exist due to genetic problems, environmental influences and lifestyle. In addition, different ethnic groups hold different perceptions and expectations that relate to health and health care. The fact that health services may not be sensitive to various cultures may lead to an unwitting display of racism and discrimination. This 'institutional racism' when tied with a particular groups reserved tendency to seek health care can result in an unjust provision of health care.

Diabetes and hypertension are major underlying causes of end stage renal failure. Asians have five times the rate of diabetes of the overall population. Africans have 3.5 times higher mortality rate from diabetes. While diabetes can be prevented, there are no real services to deal with prevention, particularly in ethnic communities. Hypertension has a similar profile, with more than one in four people of African origin suffering from it, and Asians experiencing a mortality rate 1.4 times greater than the national average. Yet opportunities for culturally sensitive health promotion amongst these people to access appropriate health services remain remote.

Despite this, the aim should not be to create separate services as this approach results in second-rate care, but to achieve a high standard for the total population, with special attention paid on certain issues to particular groups. Rigorous ethnic monitoring would facilitate this type of appropriate planning, but as yet, no single hospital or primary care trust has achieved 100% in this area.

To conclude, it is important to tackle ill health risks, including hypertension, diabetes and smoking – it is essential to treat healthy people early. Active health promotion should be a priority in achieving this, encouraging people to plan healthy lifestyles via community based initiatives. However, before this can be done effectively the health care system must tackle the issues of racism and discrimination, as these continue to contribute to both the health and health concepts of people from first, second and even third generation ethnic minority groups.

The epidemic of chronic kidney disease in ethnic minorities



Dr Paul Roderick
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US studies in the early 80s demonstrated a higher acceptance rate for renal replacement therapy (RRT) in US blacks than the national average. This trend was later confirmed world wide in both indigenous and immigrant minority groups. The national renal review in England found a 4-5 fold higher rates of acceptance onto renal replacement therapy in Indo Asians and Blacks when standardised for age.

The most common causes of this excess are diabetic ESRD in both, hypertensive ESRD in Blacks and unknown causes in Indo Asians. There are many factors contributing including genetics, socio-economic factors affecting birth weight, lifestyle, exposure to nephrotoxins, and access and adherence with health care interventions and late referral to nephrologists.

The future demand for RRT is estimated to nearly double over the next 20-25 years, one factor being the aging of the ethnic minority populations increasing the incidence of ESRD. Due to the shortage of organ donors a higher percentage of ethnic minority patients on RRT will be on dialysis. The rise will be not uniformly spread as the concentration of ethnic minority populations varies considerably with major concentrations in certain cities. Preventative measures are essential to prevent and ameliorate the consequences of Type 2 diabetes and hypertension in these populations.

Managing chronic renal disease in minority ethnic groups – a global perspective



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There is very little data on the actual need for end stage renal failure (ESRF) provision in most developed countries, and renal replacement therapy (RRT) figures are used in most countries as a proxy. These figures fail to show what the unmet need is. Work in the US with Native Americans and African-Americans, and in Australia with Aboriginals has shown progress, but this has happened over ten or fifteen years. The role of diabetes mellitus type 2 has been the focus in modelling.

It is important to engage communities in thinking differently about accessing healthcare. Most ethnic minorities want short-term, quick fix options – prescriptions – when what they need is a long-term approach to empower and educate them about lifestyle issues that can make a difference. One example is focusing on type 2 diabetes – involving lifestyle changes and slowing down the progression of the disease.

Screening programmes have been successful in other countries, such as the Kidney Early Evaluation Programme (KEEP) implemented among the Zuni Indians in the US. Singapore, Australia and India have also had success with early screening, where first blood relatives of patients are targeted and renal disease is diagnosed early. Primary prevention focuses on early education – involving children in health, diet, and exercise. Asking patients to sign a contract agreeing to adhere to a prescribed treatment programme can also be effective – those on contract in Singapore and Australia showed a 90% reduction in disease. It should be noted however, that the content of the contract and the outcome if the person fails to adhere is unknown.

In terms of increasing organ donations, data from the US and Singapore suggests an approach that involves using existing networks with media campaigns as a supplement. A community role model – perhaps a diabetic, a health professional or a church leader – can have an enormous influence on community opinion. Live related donation appears to be one way forward, especially amongst ethnic minorities, but more research needs to be done over the issue of gender imbalance (in India 70% of live donors are women, 90% of recipients are men).

It is not enough to give out information. The aim is to engage communities, to foster debate, to promote positive messages through using the right opinion-makers, and to create a dialogue that will lead to real change.

Preventing Renal Disease: The NKRF ABLE Project



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Too many people, especially those from ethnic communities, present too late with advanced renal disease, much of which could have been prevented or treated if diagnosed early. It is crucial to identify renal disease early, and this includes identifying the preventable diseases (Diabetes Mellitus and hypertension) that can lead to renal failure. Patients are more likely to die when they present late. 42.4% of African American men presented late compared to 27.7% White men. 27.6% of those presenting late died compared with 14.6% of those presenting early and these differences were maintained at three years. Overall, late presentation is associated with a 1.6 times increase in risk of death¹.

The aim for ethnic patients is to reduce the excess incidence of ESRF and to increase the numbers receiving transplants.

The National Kidney Research Fund Strategy

The NKRF launched the ABLE (A Better Life) campaign with a position paper, an awareness campaign, promotion of research and obtaining ring-fenced funding. The Pilot Week was held in multi-ethnic Brent in July 2002 at the Brent Indian Association and Bridge Park Complex drop in centres. Professionals offered advice, medical assessment and renal screening for high-risk individuals. Brent was chosen because of its strong history of health campaigning.

Key Findings from ABLE Pilot:

- High proportion of Asians attending had traditional risk factors for renal disease
- Rates were lower in the relatively few Africans and African Caribbeans who attended
- 30% of those with DM had evidence of early DM nephropathy (microalbuminuria+)
- Highlighted limitations of serum creatinine
- Asians had lower estimated creatinine clearances
- Did not assess those without known risk factors.

Understanding the excess of end stage renal failure in ethnic communities in the UK will lead to broader understanding of renal risk and disease progression in all communities, facilitate the evaluation of screening programmes, offer the opportunity to radically reduce the numbers of individuals reaching ESRF, inform all aspects of the developing Renal National Service Frameworks, and lead to the development of a culturally competent renal service in the UK.

References:

1. Kinchen et al 2002 Ann Int Med 137:479-486



**Renal Services for Dialysis:
Commissioner and Provider
Perspectives**
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The National Kidney Research Fund, along with the School of Health and Related Research (SchARR) at Sheffield University, undertook a survey to establish how adult renal services are currently commissioned and provided in the UK. Questionnaires were sent to all 71 adult renal dialysis provider units along with commissioners responsible for renal service commissioning in the United Kingdom. 100% of providers and 82% of commissioners responded. A great deal of work and pressure was exerted to make sure the response rate was high in the hope that the survey would accurately reflect the services available for adult dialysis. The results were as follows:

- As of July 2002, approximately 18,900 adults were receiving dialysis in the UK. This represents a 20% increase from the 1998 National Renal Survey.
- 68% of patients received unit haemodialysis, 2.6% home haemodialysis, 20.7% continuous ambulatory peritoneal dialysis, and 8.8% automated peritoneal dialysis.
- 27% of units have no patients on home dialysis and only 52% have a conservative management programme for patients who do not wish to receive dialysis or for whom it is inappropriate.
- Commissioners and providers identified lack of funding, space, facilities and staff as problems constraining the choices offered.

Meeting the Need

There have been ongoing concerns that patients with kidney failure face inequalities of access to appropriate treatment. The recent reorganization within the NHS, involving more Primary Care Trusts as commissioners, along with the development of the National Service Framework (NSF) for Renal Services, provides an opportunity for improvement.

Most units operate at maximum capacity. 58% had no staffed, functional, vacant haemodialysis slots on the date the survey was completed.

- Over 90% of provider units had experienced difficulty accepting patients out of their own area during the previous year, although 65% of commissioners felt able to always commission and fund this treatment. Over 75% of haemodialysis units had difficulty in arranging the permanent transfer of patients who moved to different parts of the country.
- The number of haemodialysis patients using an arterio-venous fistula varied from 30-100% between different units with the majority above 70%. The average waiting time for elective fistula surgery ranged from one to 104 weeks, with a mean of 13.7 weeks. Waiting times were significantly increased in the 29% of units without a dedicated vascular access surgeon.
- Over 90% of commissioners, but less than half of providers felt they had an effective commissioning process. 74% of providers felt that the process would allow expansion of the service if they had physical capacity. More than 75% of providers planned an expansion in the next three years.
- Less than one third of commissioners and providers have separate arrangements for acute renal failure. 15 units were unable to accept patients for treatment at some stage during the previous six months.

This survey highlighted the gaps that exist between providers and commissioners. It shows how renal services are currently commissioned and provided across the UK, and identifies a service that is expanding but faces various constraints between regions and the limited ability to deliver better service without further investment.

Public and Patient Involvement in Planning Healthcare



Mrs Sharon Grant
Chair of the Commission for Public and Patient Involvement in Healthcare (CPPIH)

Established on 1 January 2003, the Commission for Patient and Public Involvement in Health (CPPIH) works with a wide range of organisations including other healthcare groups, government bodies and voluntary organisations, in an effort to present real public needs to the government. Headquartered in Birmingham, the commission has nine regional centres and is responsible for setting up 571 Patient and Public Information Forums (PPI Forums) – one for each Primary Care Trust and NHS Trust in England.

The functions of the CPPIH are:

- Promoting patient and public involvement in decision-making about health
- Recruiting and appointing members of Public and Patient Information Forums (PPIFs)
- Providing staff to set standards and manage performance
- Setting standards and performance managing a new independent Complaints Advocacy Service
- Putting forward the views of patients and the public at a national level including undertaking reviews on policies and services.

It is a fact that there is a need for earlier diagnosis in kidney disease, and also for better access to information. While there are many competent people working within these areas, the system often fails to deal with renal patients' needs. It is difficult to find out what to expect as a patient or as a carer. The CPPIH plans to be active in helping to resolve this.

A large-scale system will be established under the Commission with the aim of involving patients in health. This will require a huge culture change and it will probably be five years before the full effect is evident.

The Commission will emphasise raising localised and customised awareness of renal disease through local networks, focusing on early detection, health education and organ donation awareness, and also creating a dialogue with healthcare workers, targeting awareness and attitudes. The Commission will also identify best practice, define populations at risk and provide adequate provision and promote research.

Meeting the Challenges of Organ Donation and Transplantation



Organ Procurement in the United States – The Fort Worth Experience
Dollie Gentry, Donation Clinical Specialist
LifeGift Organ Procurement, USA

LifeGift is one of 59 Organ Procurement Organisations (OPOs) in the United States. OPOs are not-for-profit organisations responsible for identification and care of organ donors, organ retrieval, organ preservation, transportation, and data follow-up regarding organ donors. LifeGift serves 109 counties in North, Southeast, and West Texas with a population of 7.6 million people.
www.lifegift.org

The Fort Worth Experience.

LifeGift Fort Worth have increased the number of donors to 37.9 per million of the population, in comparison with the national average of 27.1 per million. Out of 13,500 potential organ donors, only 48% actually become donors. The following reasons explain why potential donors sometimes fail to become actual donors:

- The hospital is unable to identify potential donors.
- The hospital is familiar with criteria for donation.
- Lack of consent.

The national goal was to increase donation by 10-20%. LifeGift set out to achieve this by implementing some new core strategies that included concentrating efforts on the most productive hospitals (90% of donors came from 10% of hospitals), and utilising in-house co-ordinators to provide early and ongoing interaction with hospital staff and family members. The increase in donations nation-wide was 6.4%, LifeGift saw an increase of 18%.

The LifeGift strategy advocates Specialist Donation intervention when:

- Death is imminent
- The brain is severely damaged
- Glasgow Coma Scale (GCS) scores are 5 or less
- Mechanical support is about to be discontinued
- Three brain stem reflexes are absent

It is essential that Special Requestors or Donation Specialists get involved with the family as soon as possible as the way the family is approached for donation is vital. It is our experience that families who are given detailed information are five times more likely to give consent. Additionally, families who meet with a donation professional are three times more likely to give consent, and those who knew the patient's wishes are seven times more likely to give consent.

Approaching consent – In House Coordinator (IHC) and Special Requestors (SR)



Tina LeVert
Donation Clinical
Specialist
LifeGift Procurement,
USA

For people waiting on transplant waiting lists, consent is crucial. Without it, they will continue to wait and continue to die. At LifeGift the In-house Donation Co-ordinators and Special Requestors fulfil a vitally important role in achieving consent by following these guidelines:

- Meet the family early
- Establish a rapport
- Inform the family of Special Requestor Role
- Offer assistance
- Explain procedures and hospital policies
- Accompany the physician during any dialogue with the family
- Listen
- Determine who the family leader/decision maker is
- Assess whether the family understands the meaning of brain death.

Many Blacks and other minorities have bad impressions of the predominantly white health care system. This has come about in part because of historical injustices, such as the Tuskegee experiment, where black men were given placebos for syphilis so that white doctors could study the long-term effects of the disease. LifeGift advocates that a Special Requestor or Donation Co-ordinator should be someone who identifies with African-American or Hispanic culture, can speak the language if necessary, and who can connect with the family and give them confidence, assuring them that the right decisions will be made. Rather than a white person saying, Blacks don't donate, a Special Requestor can build rapport by saying, Saving lives begins with us.

This project, sponsored for two years by Lambeth Southwark and Lewisham Health Authority, commenced in July 2001. It consisted of two phases: research and networking (2001-2002) and outreach programmes (2002-2003). It began as a response to the disproportionate number of black people with end stage renal failure and the low numbers of blacks registered as organ donors (>1%) due to lack of awareness, religious and cultural beliefs, fear of the unknown and prejudice.

The project put forward a number of initiatives to address the problem over the past year, including a community involvement Black Health Week, an Organ Donation Health Awareness Fun Day, and a Choice FM Radio Phone-In. ACODAP also networked with community groups, held church programmes, recruited for a volunteer network group and held a Health Professionals' Study Day.

It is hoped that secure funding will be obtained to continue the project, focusing on college programmes, church programmes and conferences for Black church leaders. The development of a volunteer network, greater involvement in community events, development of collaborative groups and further research is also planned. ACODAP hopes that people involved in similar work can share information and work cohesively for stronger results.'

African Caribbean Organ Donation Awareness Project (ACODAP)



Cynthia Davis
Project Manager
Kings College Hospital
Trust

Allocation of Organs

From a biological point of view, diversity is a positive thing, there is strength in diversity. Evolution has shown that populations do not carry on unless they are diverse – those without defective genes are allowed to continue. This often clashes with modern notions of sociology and social justice and it is a difficult balance – making sure that decisions are handled evenly and with fairness.



Dr Phil Dyer
President, British
Transplant Society

Transplantation is the most effective form of treatment for renal failure. There are much higher survival rates at both one-year and five years post-transplant than compared to dialysis. The problem is supply and demand. There is an inadequate supply of organs in the UK that leads to rationing and demands careful use of existing organs. In the UK today, transplantation is not a right – it's a privilege.

How are organs allocated?

Each transplant centre should have a written policy that defines its allocation process in a form that can be presented to patients and society in general. The aim should be to enhance the overall availability of organs, to strive for justice and medical utility, to provide reasonable opportunities for recipients, to respect patient autonomy and to prioritise long waiters.

Overall allocation objectives:

- Maximise organ availability
- Maximise patient and graft survivals
- Minimise waiting times
- Minimise deaths
- Maximise opportunities for those who are biologically disadvantaged
- Minimise costs
- Provide accountability and public trust

But to achieve this effectively we need to be more proactive in health promotion and donation awareness work. The excellent work of LifeGift and ACODAP are an example that should be replicated many times over.



Mr Chris Rudge
Medical Director
UK Transplant

Ethnicity and Renal Transplantation

The National Transplant Database has only collected full ethnicity data since January 2002. It contains data on the waiting list and on both donors and transplant recipients. There is also data on the effect of ethnicity on the blood group of potential recipients, HLA type and matching, waiting times for transplantation, and transplant outcomes.

While 98% of donors are white, whites make up only 78% of the transplant waiting list, 14% are Asian and 6% Black. This means there is a 3-4 times disproportionate representation of minority groups waiting for a kidney. However, when they receive a transplant the outcomes are the same as for the white population.

The general principles of kidney allocation do not take gender or ethnicity into account, and the aim is equality of access for all patients. The inequalities stem from biological diversity, and the challenge is to minimise the effects of this diversity.

Some changes have already been made to address the problem. The national allocation rules have been modified to allow some O blood group kidneys to go to blood group B recipients. In addition, points have been allocated to well-matched (tiers 1 and 2) patients who have waited longer and for those who are difficult to match. These changes have had limited success in addressing the problems of ethnic minorities. Most O kidneys allocated to blood group B patients go to whites, and the points system only applies when there is a well-matched kidney. The problem is that too few ethnic minority patients are offered well-matched kidneys. Some other changes are necessary:

- Change the definition of the HLA antigens used in allocation
- Change the relevance of HLA for some or all patients
- Change the blood group rules further
- Use blood group A2 kidneys for B recipients
- Increase organ donation from Asian and black donors

More equal access to transplantation implies more sharing between transplant centres. It will need to be decided whether kidneys are a local or a national resource.

The general principles of kidney allocation do not take gender or ethnicity into account, and the aim is equality of access for all patients.

Bibliography

- Darr A & Randhawa G (1999) Awareness and attitudes towards organ donation and transplantation among the Asian population – A preliminary survey. *Transplant International*, 12, 365-371.
- Dyer P (2002) Human Rights for people registering as organ donors. *Lancet*, 360, 91.
- Dyer P (2001) Effect of Cold ischaemic time and HLA matching in kidneys from young and old donors. *Transplantation* 72, 674-678.
- Dyer P (2000) Kidney Transplants for Asian people – does biology discriminate? *Nursing Times* 96. 39-40.
- Dyer P (1998) Pre-emptive kidney transplantation: the attractive alternative. *Nephrology, Dialysis and Transplantation* 13, 1799-1803.
- Hedger N, Stevens J, Drey N, Walker S, Roderick P (2000) Incidence and outcome of pauci-immune rapidly progressive glomerulonephritis (RPGN) in Wessex, UK – a ten year retrospective study. *Nephrology Dialysis and Transplantation* 1593-1591 Vol 15 September.
- Jackson M, Peters J (2003) Developing health information systems for Black and Minority Groups using modern technology: processes and issues. *Health Information and Libraries*. In press.
- Lamping DL, Constantinovici N, Roderick P, Normand C, Henderson L, Harris S, Brown D, Gruen R, Victor C (2000) Why age should not be a barrier to dialysis: Evidence of clinical outcomes, quality of life and costs from the North Thames Dialysis Study (NTDS). *Lancet* 356;1543-1550.
- Lightstone L (2003) Preventing kidney disease – the ethnic challenge in the UK. *Kidney International* (currently in press).
- Lightstone and Woolnough, Preventing kidney disease: The ethnic challenge in Brent. National Kidney Research Fund ISBN 1-904227-04-X
- Lightstone L (2002) Renal Disease in Ethnic Communities, *British Journal of Renal Medicine*.
- Moore DA, Lightstone L, Javid B, Friedland JS (2002) High rates of tuberculosis in ESRF; the impact of international migration. *Emerging Infections*, 8, 77-78.
- Peters J, Baxter T, Pollard S (2002) Care pathways: processes that can aid development and evaluate implementation of a myocardial infarction pathway. *Journal of Integrated Care*, 6, 63-68.
- Peters, J et al (2002) The clinical effectiveness and cost effectiveness of inhaler devices used in the routine management of chronic asthma in older children: a systematic review and economic evaluation. *Health Technology Assessment*, 6, No 5.
- Peters, J et al (2001) What role do nurses play in Type 2 diabetes care in the community: a Delphi study. *Journal of Advanced Nursing*, 34, 179-188.
- Randhawa G (2003) Developing culturally competent renal services in the UK: Tackling Inequalities in Health. *Transplantation Proceedings*. 35, 21-23.
- Randhawa G (2001) The changing nature of organ procurement policies and the implications for the UK. *Journal of Health and Social Policy*, 12, 53-74.
- Randhawa G (2000) Increasing the donor supply from the UK's Asian population: The need for further research. *Transplantation Proceedings*, 32, 1561-1562.
- Roderick P, Jones, Tomson C, Mason J (2002) Late referral for dialysis: improving the management of chronic renal disease. *Q J Med* 95:363-37
- Roderick P, Jones C, Drey N, Blakeley S, Webster P, Goddard J, Garland S, Bourton L, Mason J, Tomson, C (2002) Late referral for end-stage renal disease: a region-wide survey in the south west of England. *Nephrol Dial Transplant* 17:1252-1259

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