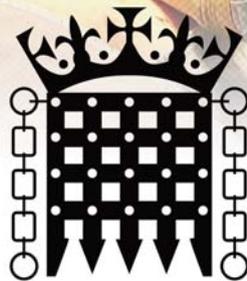


A M A N I F E S T O T O I N C R E A S E T R A N S P L A N T A T I O N

Improving kidney donation and transplantation within UK Black and Minority Ethnic communities

A REPORT OF THE FINDINGS OF
THE 2011 BME TRANSPLANT SUMMIT



Hosted by

THE ALL PARTY PARLIAMENTARY KIDNEY GROUP

The production and distribution of this document was supported by the National Kidney Federation.
Editorial control belongs to the All Party Parliamentary Kidney Group.

Contents

Title	Page
Foreword	3
Introduction	4
Background	5
The Manifesto	7
Call for Action	14
Conclusions	16
Appendices	17
1. Recent actions and initiatives	
2. The Summit programme	
3. The attendees at the Summit	

Foreword

I believe that this Manifesto will make a valuable contribution to improving the service to Black and Minority Ethnic (BME) kidney patients and will help save lives. The term Black and Minority Ethnic is an inclusive one used to cover people from South Asian (mainly Indian, Pakistani and Bangladeshi) background, those from Afro-Caribbean and African background, new migrants from for example Eastern Europe, Sri Lanka and Somalia, those from mixed heritage as well as those who identify themselves as being Black or from an Ethnic Minority in this country.

It is clear from the statistics available that little progress has been made so far in the service provided to BME kidney patients waiting for a kidney, despite actions taken by the NHS, kidney charities, BME community groups and others. We need to tackle this challenge by taking a strategic approach, by providing leadership and by working in partnership. This is an opportune time to do so because of the major changes taking place within the NHS, the Welsh proposals to introduce opt –

out, and the end of the current NHS strategy on organ donation and transplantation in 2013.

While the focus of the All Party Parliamentary Kidney Group is upon kidneys, it is important to emphasise that most of the issues raised in this Manifesto will also apply to BME patients requiring other organs. It is also important to emphasise the importance of preventative care and the role of GP Commissioning Groups in tackling issues facing BME communities.

I would like to thank everyone who participated in the excellent Summit on 29 November 2011, particularly all the speakers, the facilitators and the National Kidney Federation (NKF). It is not often that we can consider a challenge and find practical ways of dealing with it. I believe we can meet this challenge by working together. The All Party Parliamentary Kidney Group will, of course, do all it can to support the implementation of the twelve actions set out in the Manifesto.

Robert Buckland MP
Co-Chair, All Party Parliamentary Kidney Group

Introduction

The All Party Parliamentary Kidney Group consists of 129 members of Parliament and Lords. Their registered purpose is:

"To improve understanding in parliament of kidney disease and transplant medicine and promote improvements in the health and care services that are available to improve the health of people with renal failure"

The two joint chairs are **Robert Buckland MP** and **Madeline Moon MP**.

The secretariat of the group is provided by the National Kidney Federation, a kidney patient charity which is run by kidney patients for kidney patients and is registered charity number 1106735. The charity receives sponsorship from renal industries, including all the main pharmaceutical companies that are suppliers of transplant medicine.

The All Party Parliamentary Kidney Group (APPKG) monitors both the provision of dialysis services and transplantation in the UK. It maintains an active interest in all matters of Chronic Kidney Disease (CKD).

As part of its programme the APPKG held a BME Transplant Summit in the Palace of Westminster on 29th November 2011 to which all leading BME community groups and renal stakeholders were invited. The purpose of the summit was to highlight the shortage of transplant opportunities within BME groups in the UK to a broader audience and to identify what actions were necessary to alleviate this shortage and increase the number of transplant operations taking place each year. The APPKG believes that this would extend the life of many patients, would improve their quality of life and save the NHS money in both the short and the long term.

This report presents to a wider audience the finding of the Summit.

Background

Kidney donation and transplantation in Black and Minority Ethnic communities in the UK continues to be a major challenge, despite some actions and initiatives which have taken place in the last few years. One of the main reasons for this is that it is a complex issue; it involves issues such as ethnicity, class and faith as well as those relating to patients with a serious disease, many of whom face multiple deprivations such as poverty, poor housing and unemployment. Another reason is that, while ad-hoc actions or initiatives have been led by committed individuals and organisations, there has been no national strategy to tackle the overall challenge or systematically monitor the impact of these developments. A list of some of the actions and initiatives is set out in Appendix 1. There is limited statistical information available to provide a detailed analysis of the current situation. However, an overall understanding of the situation can be summarised from the following data.

- BME patients are disproportionately represented among patients receiving renal replacement therapy (either dialysis or transplantation) because of a number of reasons. For example, prevalence of Type 2 diabetes is up to six times greater among South Asian and African-Caribbean communities and diabetes is a major cause of kidney disease.
- People from BME background represent around 28% of those waiting for a kidney transplant (around 16% are from South Asian background and around 9% from African-Caribbean background). In comparison, BME communities constitute about 11% of the UK population.
- Around 3% of those who have signed up to the Organ Donor Register are from BME communities.

Background

- The significant increase in the number of people nationally on the ODR (now over 18 million) in the last few years has not been matched within the BME communities.
 - The target set by the Department of Health to increase the number of all organ donations from deceased donors by 50% by 2013 has resulted in an increase of 25% over the last three years i.e. up to March 2011. The number of such donations from BME donors has increased from 32 to 40 during the same period.
 - Consent rates from close relatives of potential BME donors continue to be significantly lower than white donors.
 - The average waiting time for an organ for someone from Asian or Black background is about 30% longer than that for a white patient, about 3 years for a white patient compared to about 4 years for an Asian or Black patient.
 - The number of kidney transplants from living donors has increased for both South Asian and Black communities, and matches the increase from white donors over the last three years.
- In summary, the overall situation is worrying. The key initiatives taken over the last three years have not resulted in acceptable outcomes, since limited progress has been made. The situation is likely to get worse with the projected growth in our population as well as a demographic shift to longer life expectancy in this country.**

The Manifesto

The Manifesto consists of *four* strategic challenges supported by *twelve* specific actions...

Strategic Challenges

FIRST CHALLENGE

The first strategic challenge is the need to take ownership of this issue and to provide leadership at a national level. There are many different views on why we have not made progress in increasing donation and transplantation despite various actions which have been taken in recent years.

Some believe that the current provision is available to all and it is up to the BME communities to deal with the specific religious or cultural issues they face. Others believe that this is mainly a generational issue and, as time passes, we will have more people from BME communities born and educated in this country and this will resolve the issue. However, most people accept this is a major issue which needs to be resolved but do not know what we should do. Some are reluctant to be involved in case they cause offence and tend to leave it to "experts". Many have very limited understanding of the basic religious and cultural backgrounds of BME communities and often do not know how to effectively engage with

BME patients. This affects everyone providing services to renal patients; those working in hospitals, GPs, kidney charities, Kidney Patient Associations, NHS, NHSBT, BME community groups, pharmaceutical companies and others. There is an urgent need for all to take ownership of this issue and not rely on others to deal with it. Linked to ownership is the importance of providing national leadership in this area. To date, no one has provided the strategic leadership needed. Leadership in this area has to involve all those providing services to patients and representatives of as many BME communities as possible. The new National Commissioning Board needs to be represented at a senior level in these arrangements.

The first strategic challenge is for everyone involved in providing services to renal patients to take ownership of the urgent need to improve organ donation and transplantation rates for BME patients and to establish an inclusive leadership arrangement at a national level.

Strategic Challenges

SECOND CHALLENGE

The second strategic challenge is for all service providers to review how they are meeting the needs of BME kidney patients and to determine what more they can do. Some providers probably do very little at present while others have given this priority for many years. Examples of successful work in this area have one common feature; the work either involves people from the particular BME group(s) who are employed by the service provider or there is a joint partnership between the service provider and specific BME religious or cultural group(s). Regrettably, there are very few people from BME groups employed by the service providers in this area and this is a major issue which needs urgent consideration by service providers. Clearly this may need additional resources and there are currently huge pressures on resources within the NHS. However, the huge savings to the NHS if we decrease the number of patients who are on dialysis and increase the number who have a transplant needs to be emphasised in any decisions about resources. Another issue relates to the importance of having a senior person within the service provider to take

overall responsibility for how the needs of BME patients are being met. Each service provider should include this issue in its annual development plan, with clear objectives and outcomes, which should be monitored by the Senior Management Team as well as the Executive Board. This would also help organisations meet their requirements under the Single Equality Act and the development of the Single Equality Scheme. Clearly it is for each service provider to decide what more it can do. The following questions may be helpful.

- How will the new National Commissioning Board fulfill its responsibilities in this area?
- What are NHSBT's plans to address this challenge? In particular, what more can Trust Donation Committees (TDC), lead clinicians, Specialist Nurses for Organ Donation (SNOD) and Transplant Coordinators do? What training in dealing with BME patients is provided? How can we increase representation from people from BME background in the ODCs, and among lead clinicians, SNODs and Transplant Coordinators?

Strategic Challenges

- How do GPs or Clinical Commissioning Groups fulfill their responsibilities in this area? Do they have the necessary information themselves? Are they able to provide appropriate information and advice, including some in our community languages, to patients from BME background?
- How are NHS Trusts providing nephrology, dialysis or transplantation services meeting the needs of BME patients? For example, what is the take-up of Renal Patient View among BME patients?
- What further research do we need to undertake in this area? What are the plans for research in this area? How will this be funded? What are the future initiatives planned by Kidney Research UK? What plans has the National Institute for Health Research got for research in this area?
- What more can kidney charities do? Do they have the necessary funding, expertise and information to support BME patients? What more can Kidney Patient Associations do to involve more patients from BME background in their work?
- What more can BME community groups do? Are they pro-active in working with others to meet the needs of kidney patients in their communities?

The second strategic challenge is for all service providers to review what they are currently doing to meet the needs of BME kidney patients and to determine what more they can do to meet the challenge.

Strategic Challenges

THIRD CHALLENGE

The third challenge is about improving partnership working between service providers and BME religious and community groups. There are examples of good partnership working with a few BME communities, such as the Hindu Forum and the Seventh-Day Adventists. A significant report on Faith and Organ Donation was published by 2010 by the Department of Health and the Organ Donation Campaign. It sets out views on organ donation from six major faith groups in this country (Buddhist, Christian, Hindu, Jewish, Muslim and Sikh) and makes recommendations related to:

- How to develop trust and transparency
- How to increase public engagement
- How to raise awareness and provide education and training
- How to improve the process of registration for organ donation.

It is clear from this research that for many BME communities faith is an important consideration in making decisions about donation and transplantation. Partnership working between BME communities and service providers, both at national and local levels, seems to be patchy. For example, there is little evidence of engagement with the Bangladeshi community or the newer migrants from Poland, Somalia and Sri Lanka. A systematic approach to working in partnership with all major BME communities needs to be developed, building build on the successful partnerships already established. However, it is important to carefully consider the following.

- Recognise that the capacity for working in partnership by different BME groups locally or nationally will vary greatly. Many will need advice, training and support from service providers. In particular, it is important to build long term arrangements based on mutual trust and respect. Many will need financial support to employ a member of the community to take the lead in developing the partnership and sustain

Strategic Challenges

it. It is important that close partnerships be established with the main national BME groups so that they can support developments in their communities at a local level.

- Appreciate that effective communication about donation and transplantation with members of the BME communities is essential. This may involve translating material in appropriate community languages, using DVDs, web-sites and Facebook; or attending major events organised by the communities.
- Involve key members of the BME communities in the partnership. These include community or faith leaders, patients and donors from the

community as well as health professionals from the community.

- Take advantage of using the partnership to promote healthy living or other areas of concern such as diabetes or high blood pressure.
- Ensure that clear objectives are set for the partnership and that the impact of projects is measured on a regular basis.

The third strategic challenge is to improve partnership working between service providers and BME religious and community groups and to nationally monitor progress.

Strategic Challenges

FOURTH CHALLENGE

The fourth and final strategic challenge relates to improving data collection, analysis and its use. The current arrangements for doing so are poor. The ethnic categories we publish for those on the Organ Donation Register, for donors and for recipients need to be reviewed. For example, we publish data under the Asian category for everyone from Indian, Pakistani and Bangladeshi background. These are large and very different communities and the data should be available separately for each of the major Asian communities. One way to do this is to use the ethnic categories used in the Census. We currently do not collect any data on religion. Given the importance of faith mentioned above, this needs to be addressed urgently and sensitively. GPs also collect data on ethnicity and it would be helpful to consider how we can establish a consistent approach to collecting data. The data we currently collect on ethnicity is not always complete. While it is recognised that it is entirely for the individual to provide such data, the importance of the data and how it can help individuals as well as the whole service needs to be highlighted. Individual

hospitals are not very good at collecting and providing data on ethnicity on renal patients. The Renal Registry which publishes an annual report on renal data provided by hospitals continues to express concern about the number of renal centres which provide incomplete data, particularly on ethnicity. In addition, the Renal Registry does not properly analyse the data on ethnicity it does receive. This means that it is not possible to draw meaningful conclusions from the Renal Registry report. The importance of the collection of relevant data on ethnicity and religion, together with proper analysis and publication on a regular basis would enable all to target resources at the most urgent needs within the BME communities. For example, anecdotal information indicates that Bangladeshi women waiting for a kidney transplant are probably least likely to receive a transplant but we do not have the data to check this. We, therefore, cannot target resources at this group of patients.

The fourth strategic challenge is to improve data collection and analysis on ethnicity and religion so that we can use this to target resources where most needed.

Call for Action

Call for Action: - The four strategic challenges outlined earlier have resulted in 12 recommendations for action. The first strategic challenge has 2 actions linked to it, the second 6 actions, the third 2 actions, and the fourth 2 actions.

The term service provider means all those who provide renal services and include kidney charities, where appropriate.

- **Action 1:**

All service providers to recognise that more needs to be done to improve donation and transplantation for BME patients and to take ownership in meeting this challenge.

- **Action 2:**

A national BME Organ Donation and Transplantation Leadership Group, involving service providers and representatives from the main BME communities, to be established with the remit to provide leadership in improving the current situation, to monitor progress, to share good practice and to report annually on progress.

- **Action 3:**

All service providers to appoint a senior person to take responsibility for ensuring that the service provider regularly reviews its work related to BME patients waiting and that this features in its the annual development plan.

- **Action 4:**

All service providers to consider ways in which they can employ more staff from BME background.

- **Action 5:**

All service providers to familiarise themselves with existing successful initiatives relating to prevention, education, awareness and increasing donation and transplantation in BME communities and establish appropriate training for their staff in understanding the religious and cultural aspects of the main BME groups in this country.

Call for Action

- **Action 6:**

The new National Commissioning Board to set out clear outcome standards to meet the specific needs of BME patients in its specification.

- **Action 7:**

All individuals and organisations undertaking or funding research, including Kidney Research UK and the National Institute for Health Research, to consider ways in which further research initiatives can help improve the provision for BME patients.

- **Action 8:**

BME religious and community representatives to consider what they can do to improve the provision for kidney patients in their communities and be proactive in developing sustainable partnerships with local and national service providers, as appropriate.

- **Action 9:**

All service providers, including Kidney Patient Associations, to develop a plan for establishing sustainable partnerships with

BME communities at a local or a national level, as appropriate.

- **Action 10:**

The BME Organ Donation and Transplantation Leadership Group mentioned in 2 above to undertake a mapping exercise of current partnerships, support the development of new partnerships mentioned in 9 above and to report annually on progress.

- **Action 11:**

NHSBT, hospitals and the Renal Registry to review the current arrangements for collecting, analysing and publishing data related to ethnicity, to ensure it is consistent with the Census and GP data, and to begin collecting data on religion.

- **Action 12:**

The Renal Registry to ensure that it receives complete data on ethnicity from all renal centres and to fully analyse and publish all data related to BME groups it receives.

Conclusions

There has been little improvement in the number of kidney transplants among BME patients over the last few years, despite actions taken by the NHS and committed individuals. The situation is likely to get worse in the future unless we take decisive action. This Manifesto, produced following discussion at the Summit organised by the APPKG on 29 November 2011, identifies four strategic challenges and twelve actions to improve the situation.

We hope that parliamentarians, policy makers, service providers, kidney charities, BME community representatives and patients will use the Manifesto to challenge what is happening at present and ensure that the issues raised here are taken on board. The current NHS strategy arising from the Organ Donation Task Force comes to an end in 2013 and NHSBT has been given the responsibility to develop the future strategy. We expect the new strategy to take full account of this Manifesto, particularly the twelve actions.

Appendices

Appendix 1:

Recent Actions and initiatives

1. Media campaigns by NHSBT to increase the number of donors from BME communities: www.organdonation.nhs.uk/blackandasian
2. Peer Educators and Awareness Initiative: www.kidneyresearchuk.org/research/health-equality-in-bme.php
3. Faith and Organ Donation report 2010 : www.theodc.org.uk/Faith+and+Organ+Donation/49/
4. Hindu Forum initiative: info@hfb.org.uk
5. Seventh-Day Adventist initiative: Resource section at www.adventist.org.uk
6. Organ Donation and Islam: <http://mhsn.org.uk/?p=155>

Appendix 2:

All Party Parliamentary Kidney Group SUMMIT Grand Committee Room, Westminster Hall, House of Commons on:

"Kidney disease and Transplantation in culturally diverse groups, including Black and Minority Ethnic groups"

- 3.00 **Welcome and introduction:**
Robert Buckland MP, Chairman of the APPKG
- 3.05 **Overview of kidney disease and transplantation in culturally diverse groups:** Kirit Modi, Vice-Chairman, National Kidney Federation
- 3.25-4.10 **Case studies**
- 3.25-3.35 Peer Educators & Awareness Initiatives: Charles Kernahan, Chief Executive, Kidney Research UK

- 3.35- 3.50 Faith and Organ Donation Project: Komal Adris, Associate Research Fellow, University of Bedfordshire
- 3.50 -4.00 Seventh-day Adventist Project: Sharon Platt-McDonald, Director for Health, Women's and Disability Ministries, British Union Conference of Seventh- day Adventists
- 4.00-4.10 Hindu project: Bhartiben Tailor, General Secretary, Hindu Forum of Britain

4.10-4.30 Refreshments

4.30- 5.15 Discussion groups

- Group 1: How can we improve partnership working between culturally diverse groups and service providers?
Facilitator: Rosemary Macri, British Kidney Patient Association, Scribe: Meena Modi
- Group 2: What more can service providers (NHS, NHSBT, hospital staff, GPs, charities) do to improve the situation?
Facilitator: Neerja Jain, Project Manager, Kidney Research UK, Scribe: Tim Statham
- Group 3: How can we improve data collection and analysis and its use?
Facilitator: Bhartiben Tailor, Scribe: Margaret Parkin
- Group 4: How can we get everyone to take ownership of this challenge?
Fiona Loud, Chair, Kidney Alliance, Scribe: Joni Thorpe
- 5.15- 5.30 **Feedback from discussion groups:**
Kirit Modi
- 5.30-5.55 **Open Forum and next stages:**
Tim Statham, Chief Executive, NKF.
- 5.55-6.00 **Conclusions:** Robert Buckland MP.

Appendices

Appendix 3: Attendance List

Dr Pinakin Patel Trust	East & North Hertfordshire NHS	Jane MacDonald Asim Yusuf	British Renal Society Muslim Healthcare Student Network
Marion Higgins	National Kidney Federation Chair	Paul Gibbs Usha Shah	Give a Kidney - One's enough Peer Educator Kidney Research UK
Triona Norman Obadah Ghannam	Department of Health The Muslim Healthcare Student Network	Muhammad Waqar Lloyd Dalton- Brown	University of Bedfordshire Lay Chair Lister Hospital Organ Donation Committee
Tasmin May Ray Mackey	NHS Blood and Transplant National Kidney Federation Treasurer	Keith Rigg Pankaj Dave Adnan Sharif Dr Sam Afolami	Transplant 2013 Kidney Research UK QEHB - South Asian Health Clinical Lead Watford Hospital Organ Donation Committee
John Crookenden	Addenbrookes Transport Association	Khalid Tawlik	Muslim Student Healthcare Network
Len Gooblar Saira Waraich	Abbott Labs The Muslim Healthcare Student Network	Chris Van Roon Orin Lewis	Researcher Robert Buckland MP African Caribbean Leukaemia Trust
Louise Barr Dr Naeem Ahmed Owen Davis Marsella De Sousa Bhupinder Manz Diviash Thakrar Sally Johnson	Selfless Charity Selfless Charity NHS Blood and Transplant BKPA West London KPA Hindu Healthcare Society National Health Service Blood and Transplant	Anjie Chhopia Joni Thorpe Margaret Parkin	Peer Educator Kidney Research UK Senior Office Administrator Nation Kidney Federation Office Manager National Kidney Federation Chief Executive Kidney Alliance Kidney Research UK
Chris Burns-Cox Sonia Clarke-Swabey	Give a Kidney - Just One National Health Service/ Seventh Adventist Church	Fiona Loud Neerja Jain	Project Development Manager Chief Executive National Kidney Federation National Kidney Federation Vice Chairman
Angy Elsghir	Muslim Healthcare Student Network	Kirit Modi	Lister Kidney Patient Foundation National Kidney Federation Secretary
Daniel Kajumbe Partha Das Emyr Harries	CMEAC (Church of England) NHS Kidney Care Senior Policy Manager Department of Health	Meena Modi OBE Michael Abbott	National Kidney Federation Executive Committee Member
Louisa Penicleous	British Medical Society	George Brown	National Kidney Federation Executive Committee Member

Appendices

Michael Walker	National Kidney Federation Executive Committee Member	Bharati Tailor	Hindu Forum for Britain - Secretary General
Dr Richard Fluck Mumtaz Goolam Nick Holie Dr Hamed Khan	British Renal Society Royal College of Nursing Transplant 2013 Muslim Healthcare Student Network	Charles Kernahan David Whitehouse Chris Dudley Rosemary Macri	Chief Executive Kidney Research UK Baxter Healthcare BTS Secretary Chief Executive British Kidney Patient Association
Dr Iain Macphee Brendan McCarthy Shahid Muhammed	St George's University of London Archbishops Council British Kidney Patient Association - Researcher	Sue Edwards	Accounts Administrator National Kidney Patient Association
Michael Nation Robert Price	Kidney Research UK National Kidney Federation Executive Committee Member	Tess Harris Professor Davis Katz	Polycystic Kidney Disease Charity Board of Deputies of British Jews
Chetna Shamla	Peer Educator Kidney Research UK		
Denny Abbott Pete Revell	Gloucestershire KPA Head of Fundraising National Kidney Federation		
Komal Adris	Institute of Health Research University of Bedfordshire	APPKG Members Robert Buckland MP - Chair Glyn Davies MP Duncan Hames MP Madeline Moon MP (Part Mtg)	
Johnson Phillips Sejal Saglani	Department of Health Chair of Charities - BAPS		

Contact Details

The All Party Parliamentary Kidney Group (APPKG)
Secretariat
Timothy F Statham OBE
56 Sapcote Road
Burbage
Leicestershire LE10 2AU

Tel: 01455 619128
Email: tim.statham@btinternet.com

National Kidney Federation (NKF)
Charity number 1106735
The Point
Coach Road
Shireoaks
Worksop
Nottinghamshire S81 8BW

Tel: 0845 601 02 09
Email: NKF@kidney.org.uk

An electronic version of this document may be viewed at www.kidney.org.uk

Improving kidney donation and transplantation within UK Black and Minority Ethnic communities

