



Organ Donation from black and minority ethnic communities

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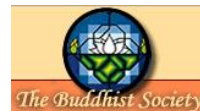
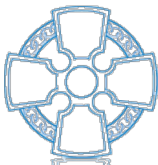
**THE BOARD
OF DEPUTIES OF BRITISH JEWS**
Proud to represent the community



The Bishops' Conference of Scotland



NETWORK OF SIKH ORGANISATIONS
UNITY IS STRENGTH



**RAMADHAN
FOUNDATION**
WORKING FOR MUSLIM UNITY



Content

- Diverse populations and impact upon demand for organs
- Diverse populations – organ donor/recipient disparity
- Engagement of multi-ethnic and multi-faith communities
- Organ donation in multi-ethnic and multi-faith communities – the potential way forward?

Content I

- Diverse populations and impact upon demand for organs

PERCENTAGE OF IMMIGRANT (FOREIGN-BORN) POPULATION

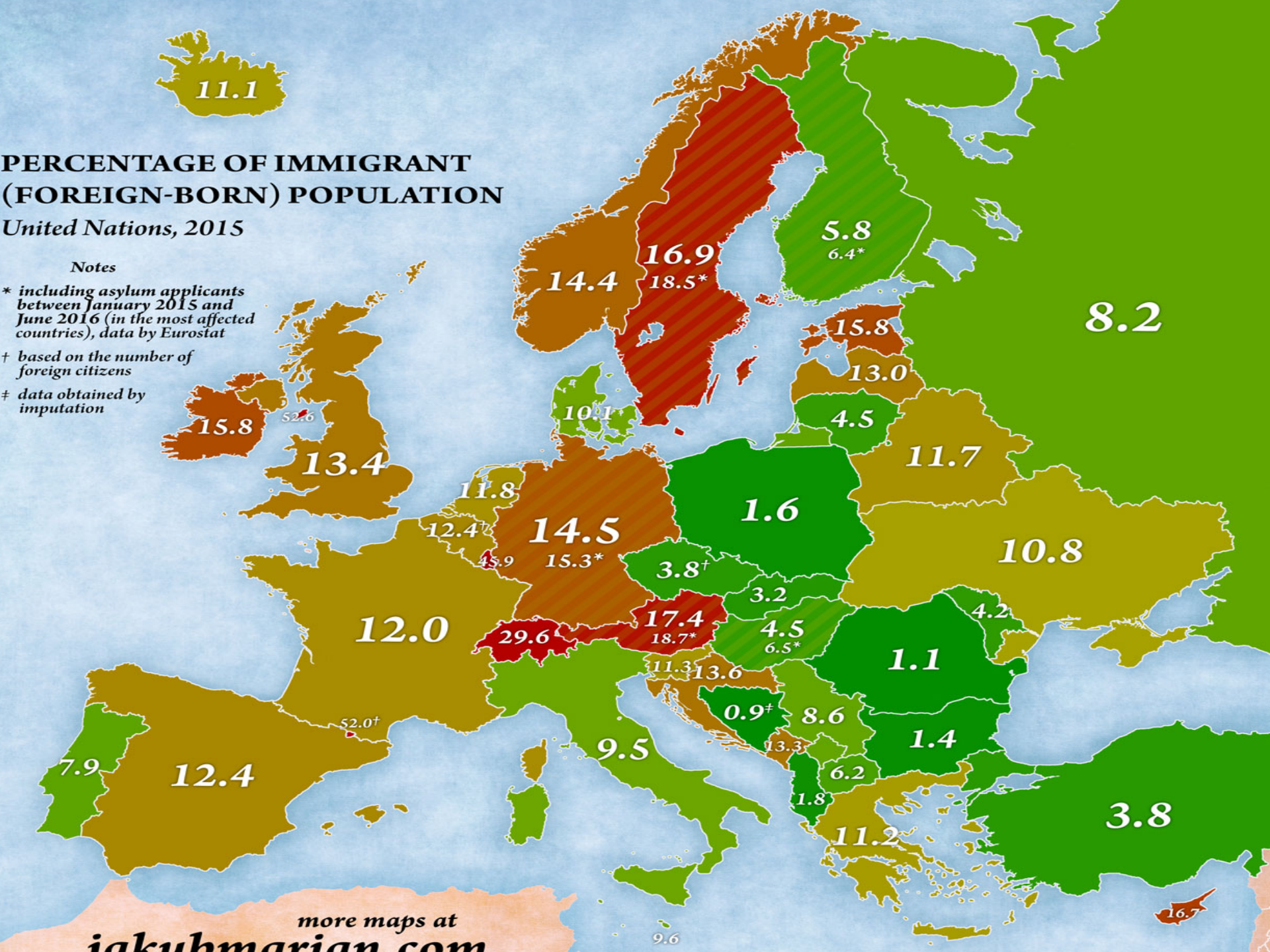
United Nations, 2015

Notes

* including asylum applicants
between January 2015 and
June 2016 (in the most affected
countries), data by Eurostat

† based on the number of
foreign citizens

‡ data obtained by
imputation



Poland

MOST COMMON COUNTRY OF ORIGIN OF FOREIGN-BORN POPULATION

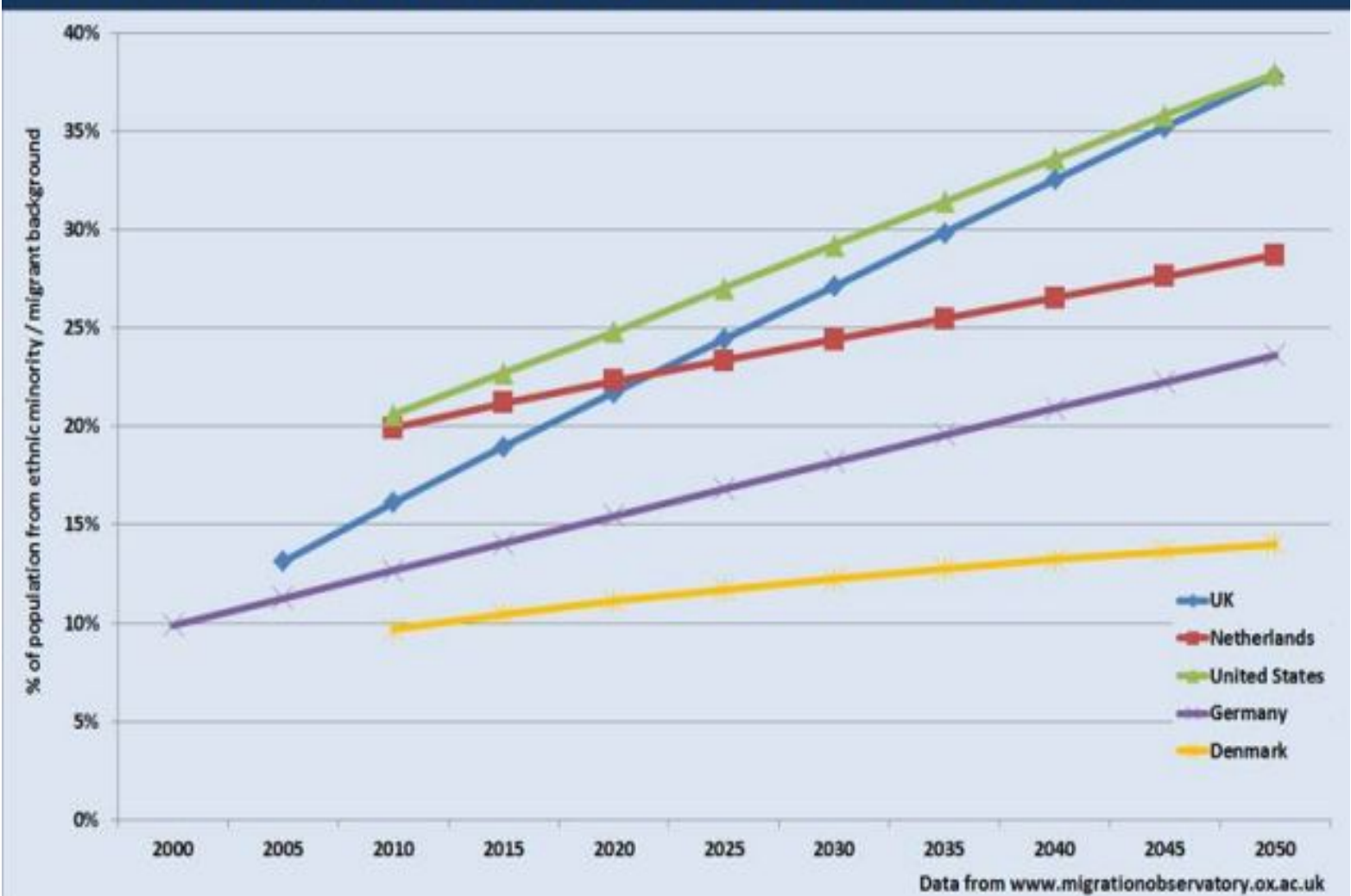
United Nations, 2015

(Note: The results remain unchanged
even when asylum applicants between
Jan. 2015 and June 2016 are taken
into account)



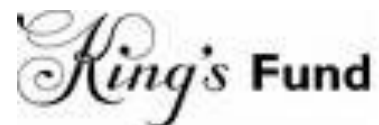
more maps at
jakubmarian.com

HOW BRITAIN IS ON COURSE TO BE MOST DIVERSE NATION



What does our research show in the UK ?

- Increased risk of diabetes, high blood pressure, kidney disease among South Asians and African Caribbean's (Polish community is fastest growing in the UK)
- Increasing number of dialysis patients from South Asian and African Caribbean communities
- Overseas transplants
- Transplant Tourism
- Reduced opportunities for transplantation
- Poor end-of-life care



Solving inequalities in kidney care requires a ‘whole systems’ research programme

- High rates of severe Type 2 diabetes (x8)
- >10 times the risk of developing kidney failure secondary to diabetes
- Late diagnosis of diabetes ?
- Late referral to nephrologists ?
- Poor patient understanding ?
- Poor end of life care ?
- Why the shortage of donors – organs, blood, tissue, stem cells, etc

Access to Kidney Care Pathway

DOI: 10.1186/1745-6215-9-118
Published online: 10/11/2012

Original Article

An examination of concordance and cultural competency in the diabetes care pathway: South Asians living in the United Kingdom

E. Wilkinson, G. Randhawa

Institute for Health Research, University of Bedfordshire, Luton, UK

ABSTRACT

The Care Pathway project used a multilevel and multimethod approach to explore access to the care pathway for diabetic renal disease. Taking what was known about the outcomes of ethnic minority patients with diabetic renal disease; the study sought to explore and further understand how and why South Asian patients' experiences may be different from the majority of population in relation to access. Through improved understanding of any observed inequalities, the study aimed to inform the development of culturally competent diabetes services. The design incorporated audits of patient indicators for diabetes and renal health at key points in the pathway: Diagnosis of diabetes and referral to specialist renal services in two years- 2004 and 2007, and qualitative individual interviews with patients and providers identified through the 2007 samples. This article describes the care provider perspective of access to diabetes care from a thematic analysis of 14 semistructured interviews conducted with professionals, at three study sites, with different roles in the diabetes pathway. National policy level initiatives to improve quality have been mirrored by quality improvements at the local practice level. These achievements, however, have been unable to address all aspects of care that service providers identified as important in facilitating access to all patient groups. Concordance emerged as a key process in improving access to care within the pathway system, and barriers to this exist at different levels and are greater for South Asian patients compared to White patients. A conceptual model of concordance as a process through which access to quality diabetes care is achieved and its relation to cultural competency is put forward. The effort required to achieve access and concordance among South Asian patients is inversely related to cultural competency at policy and practice levels. These processes are underpinned by communication.

Key words: Concordance, cultural competence, diabetes

Introduction

Previous studies in the UK had identified a greater relative risk for diabetes-related end stage renal failure (ESRF) in South Asians (those originating from India, Pakistan, Bangladesh, and Sri Lanka), [1,2] and suggested that quality of healthcare for South Asians is inadequate

and compliance poor. [3,4] There was also a low-uptake of hospital-based diabetes services, with some evidence to suggest that South Asians were subsequently referred later for renal care, and more likely to be lost to follow-up. [5] Moreover, knowledge of diabetes and its complications has been seen to be poor among South Asians. [6,7] This study - Care Pathway project - explored the concept of patient access to quality primary care - how patients gain access to services? and how services are perceived by patients and care providers? The premise being that services need to be relevant and effective if the population is to have access to quality care for improved health outcomes. The concept of access operates on multiple levels. [8] The role of healthcare providers in facilitating access includes the provision of meaningful information to support patients to make decisions about their own care. [9] Considering access in the context of primary care services and from the perspective of a diverse sample of providers can help to shed light on where, how, and for whom care could be improved in the primary care pathway for diabetes.

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DOI:

10.1186/1745-6215-9-118

Wilkinson et al. BMC Nephrology 2012, 13:157
http://www.biomedcentral.com/1471-2369/13/157



RESEARCH ARTICLE

Open Access

A multi-centre qualitative study exploring the experiences of UK South Asian and White Diabetic Patients referred for renal care

Emma Wilkinson¹, Gurdeep Randhawa^{1*}, John Feehally², Ken Farrington³, Roger Greenwood⁴, Peter Chor⁴ and Liz Lightstone⁵

Abstract

Background: An exploration of renal complications of diabetes from the patient perspective is important for developing quality care through the diabetic renal disease care pathway.

Methods: Newly referred South Asian and White diabetic renal patients over 16 years were recruited from nephrology outpatient clinics in three UK centres - Luton, West London and Leicester - and their experiences of the diabetes and renal care recorded.

A semi-structured qualitative interview was conducted with 48 patients. Interview transcripts were analysed thematically and comparisons made between the White and South Asian groups.

Results: 23 South Asian patients and 25 White patients were interviewed. Patient experience of diabetes ranged from a few months to 35 years with a mean time since diagnosis of 12.1 years and 17.1 years for the South Asian and White patients respectively. Confusion emerged as a response to referral shared by both groups. This sense of confusion was associated with reported lack of information at the time of referral, but also before referral. Language barriers exacerbated confusion for South Asian patients.

Conclusions: The diabetic renal patients who have been referred for specialist renal care and found the referral process confusing have poor awareness of kidney complications of diabetes. Healthcare providers should be more aware of the ongoing information needs of long term diabetics as well as the context of any information exchange including language barriers.

Keywords: South Asian, Patient experience, Renal complications of diabetes, Access, Care pathway

Background

Previous studies in the UK have identified a greater relative risk for type 2 diabetes related end-stage renal disease (ESRD) in South Asians (those originating from India, Pakistan, Bangladesh, and Sri Lanka) [1,2], and preliminary evidence has suggested that quality of health care for South Asians is inadequate and compliance poor [3,4]. There is also a low uptake of hospital-based diabetes services, with growing evidence that South Asians are subsequently referred later for renal care, and are more likely to be lost to follow-up [5]. Moreover, there

is evidence that knowledge of diabetes and its complications is poor among South Asians [4,6].

National Service Frameworks for Diabetes and Renal Services were introduced in the UK in 2002 and 2006 respectively. These Frameworks provide guidance to commissioners and providers of health care commissioners about the minimum standards of care that should be offered across the UK. Significantly, the Frameworks recognised the disparity between ethnic groups and promoted a focus on earlier detection and ethnicity as a risk factor to improve outcomes for diabetic renal disease across different population groups [7,8]. Furthermore, the introduction of the Quality Outcomes Framework indicators in primary care for diabetes in 2004 and estimated glomerular filtration rate (eGFR) reporting in

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Abstraction & theory building

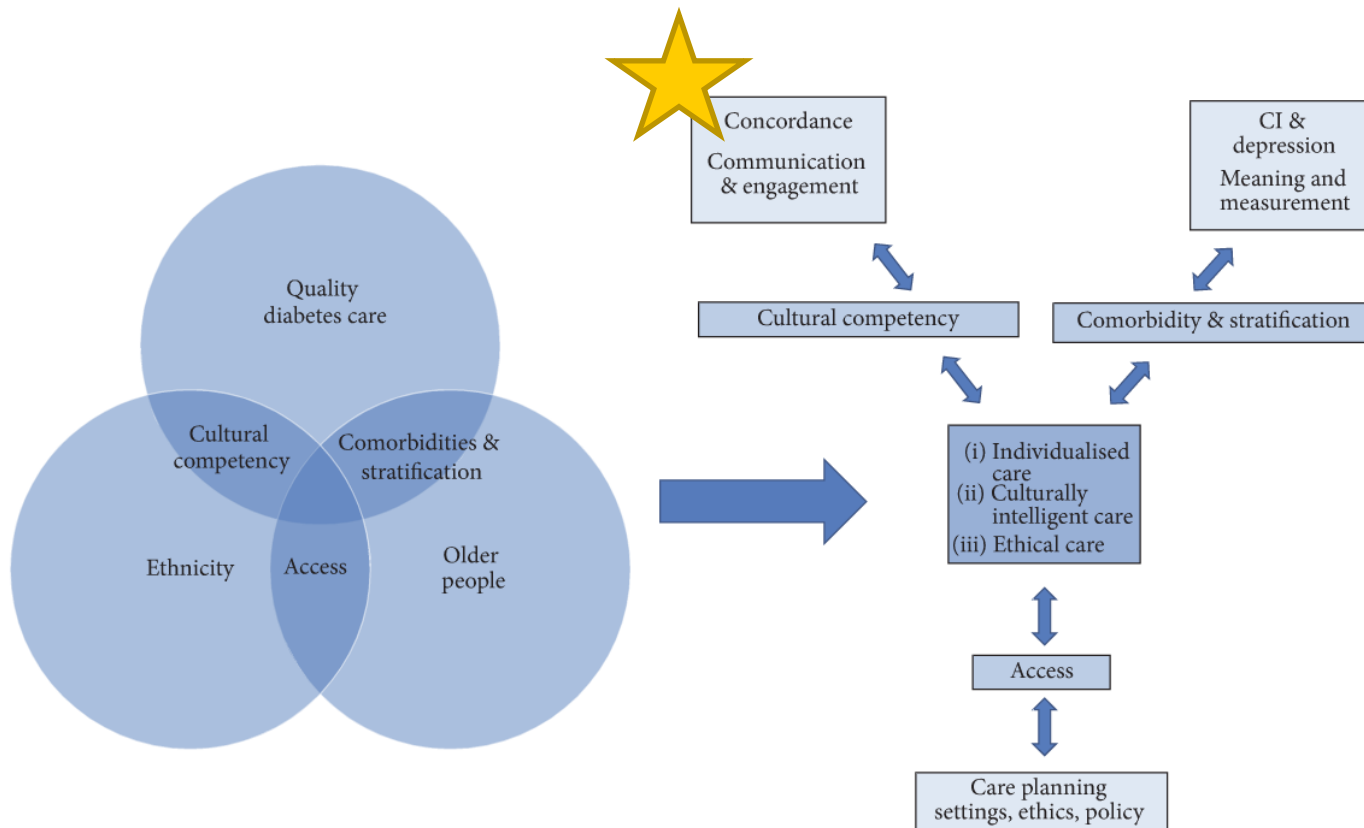


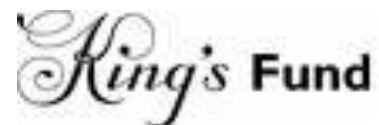
FIGURE 4: Theory building: concepts and mechanisms.

Multi-cultural vs Cross-cultural vs Intercultural approaches to organ donation (Randhawa, 2010)

Multicultural refers to a society that contains several cultural or ethnic groups. People live alongside one another, but each cultural group does not necessarily have engaging interactions with each other. For example, in a multicultural neighbourhood people may frequent ethnic grocery stores and restaurants without really interacting with their neighbours from other countries.

Cross-cultural deals with the comparison of different cultures. In cross-cultural communication, differences are understood and acknowledged, and can bring about individual change, but not collective transformations. In cross-cultural societies, one culture is often considered “the norm” and all other cultures are compared or contrasted to the dominant culture.

Intercultural describes communities in which there is a deep understanding and respect for all cultures. Intercultural communication focuses on the mutual exchange of ideas and cultural norms and the development of deep relationships. In an intercultural society, no one is left unchanged because everyone learns from one another and grows together.



Content II

- Diverse populations – organ donor/recipient disparity

National Black And Minority Ethnic (BAME) Deceased organ donor/recipient disparity

The UK BAME population constitutes:

- –11% of the population
- –31% of the organ waiting list (35% of the kidney waiting list)
- –3.5% of registered organ donors (where ethnicity is known)
- –7% of actual deceased organ donors
- -Consent rate for organ donation is lower amongst BAME families 42% (was 35% until 2017) versus White families 69.0%

What does our research say?

Qualitative studies among African-Caribbean, South Asian & Polish communities:

“They(doctors) would finish me off before I was dead.”

“I would not donate my eyes, ever, because of the ceremony prior to cremation when people come to the funeral to see the body. I don’t want to not have any eyes.”

“If the religious leaders gives us a clear cut opinion on this matter then we have less confusion. More discussion and information will help us to proceed in this direction.”

“I don’t like the idea of my relatives having to see my body been carved up.”

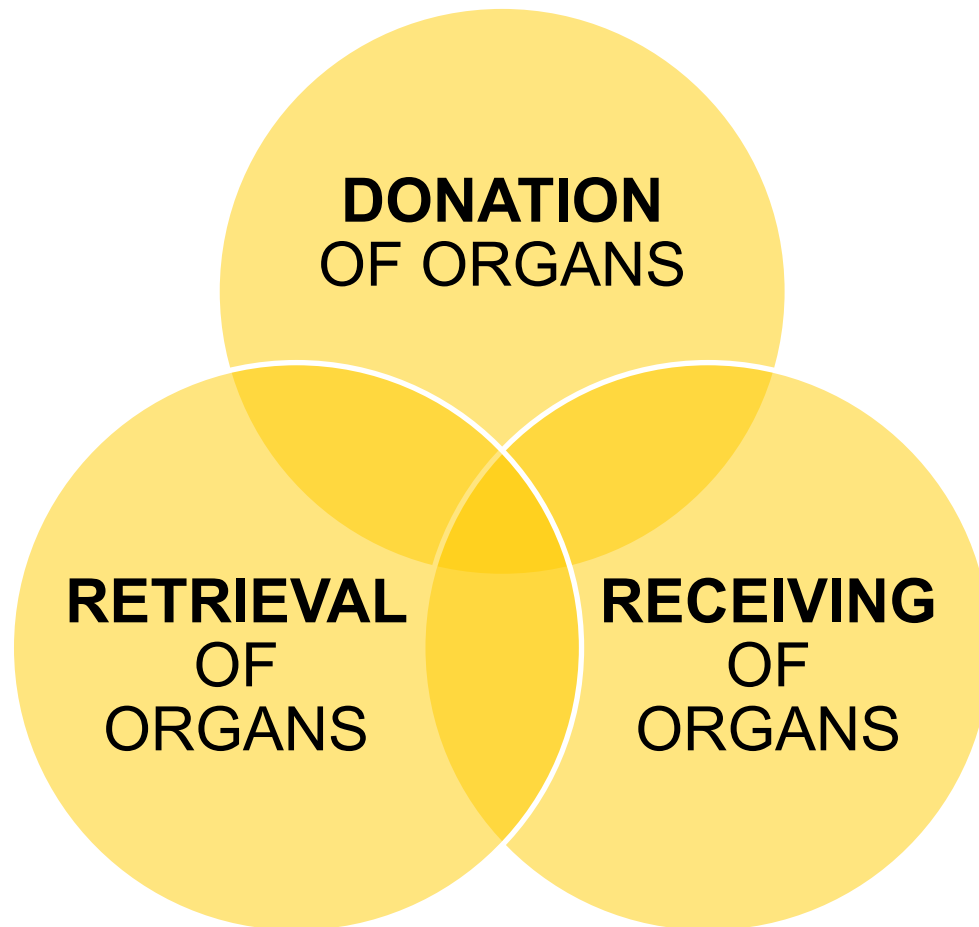
“I’m not sure about life after death, but if there is life I want to go complete.”
(Randhawa et al, 1995; 1998; 2010)

Fears with deceased donation

- Fear that Intensive care staff will not try as hard to save the patient if consent / authorisation for donation been given
- Perceived historical racism of health service
- Fear of death - barrier to thinking about/discussing donation
- Would process of transplantation maintain 'sanctity of the body'?
- How does OD process relates to burial/cremation?
- Personal unease about a loved one's organs being inside another person
- Religion could be a predisposing factor as it may be felt that deceased transplantation violate religious principles (Randhawa et al, 1995; 1998; 2010)

Public Engagement & Organ Donation

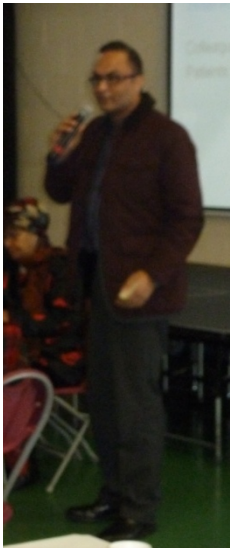
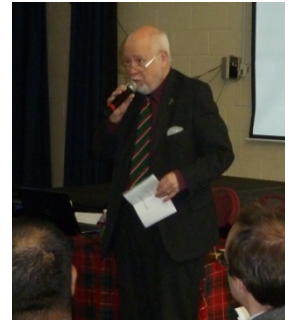
Taxonomy (Randhawa G (2011) Organ donation and transplantation – meeting the needs of a multi-ethnic and multi-faith UK population. In: Farrell A, Price D, Quigley M. Organ Shortage: Principles Pragmatism and Practice Cambridge University Press.)



Content III

- Engagement of Multi-Ethnic and Multi-Faith Communities

'Messages' and 'Messengers'



Concordance (Communication & Engagement) Making Organ Donation Chat Usual..... Community organ donation campaign launch



Living kidney donor, donor families, transplant recipients, & community leaders

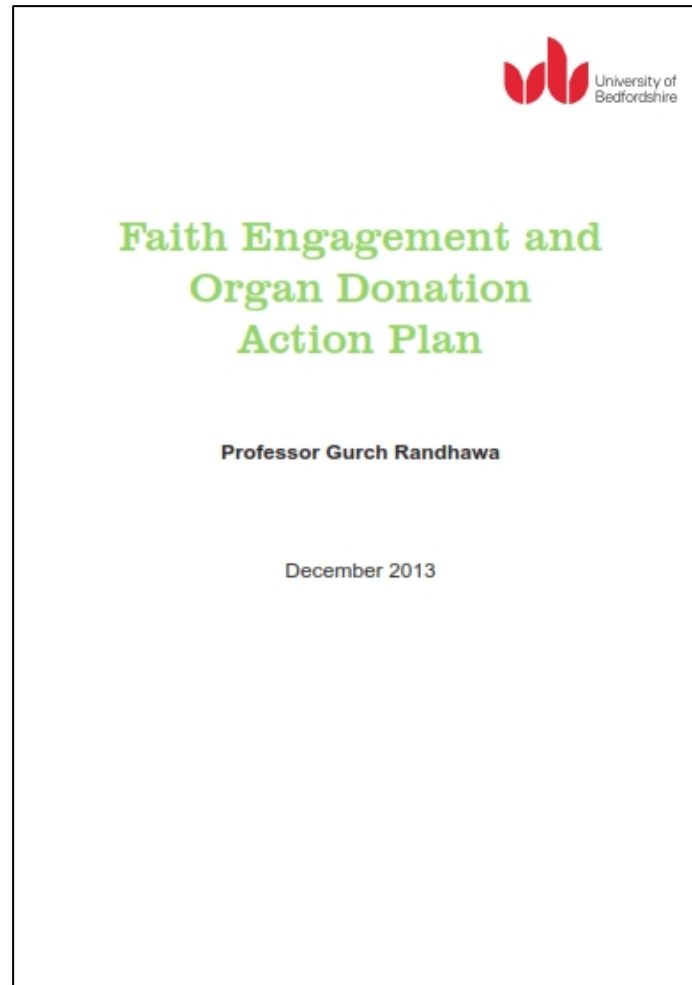
Faith and community leadership



Faith & Organ Donation Summit (NHSBT-led)

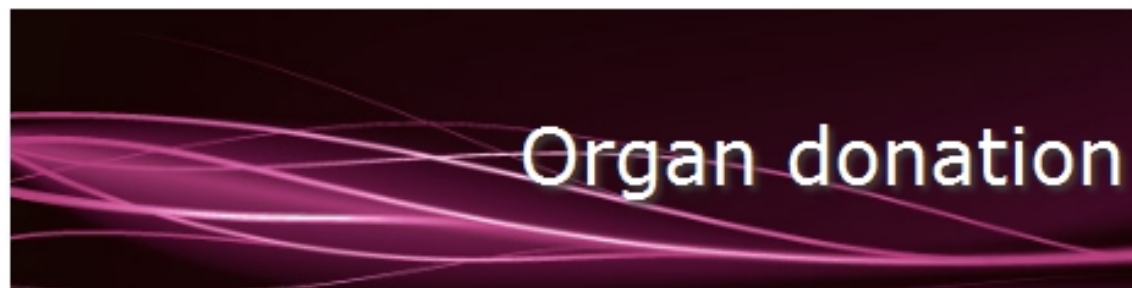


Faith Action Plan





A Christian presence in every community

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by the Bishop of Carlisle the Rt Revd James Newcome, [lead bishop on healthcare issues](#)

April 2011

As we prepare to celebrate Easter, we think of those central events in the life and ministry of Jesus: the crucifixion and the resurrection. Among other things, they speak to us of self-sacrifice and new life; self-sacrifice in the service of others and new life offered to others.

What is true spiritually often has echoes physically or socially. One such echo may be found in the sphere of organ donation where we have the opportunity to enhance, prolong or even to save another person's life through our self-giving. That donating our organs is a selfless gesture of care to others is undoubted; what is less often recognised is the extent of the need for organ donors.

Church of England

The screenshot shows the Church of England website. At the top left is the logo and name "THE CHURCH OF ENGLAND". To the right is a search bar labeled "Search website" with a "GO" button. Below the search bar is a navigation menu with links: Home, Contact Us, Document Library, Vacancies, Site Help, and Text. A secondary navigation bar contains links: About Us, Our Faith, Weddings, Baptisms & Funerals, Prayer & Worship, Education & National Society, Views, Renewal & Reform, and Media Centre. Below this is a breadcrumb trail: Home > Media Centre > Top News Releases > 2016 > 02 > General Synod backs call to encourage blood and organ donation. Social media sharing buttons for Facebook, Twitter, and Google+ are visible. The main content area features a large blue header for the news release, followed by the title "General Synod backs call to encourage blood and organ donation" and the date "17 February 2016". The text of the release describes the General Synod's decision to encourage all 16,000 CofE churches to consider becoming blood donors or organ donors. It mentions a motion from Leeds Diocesan Synod put by Father Paul Cartwright, a former police officer and now a priest in Barnsley, South Yorkshire, aimed at increasing the number of blood and organ donors in the UK. Father Paul's testimony is also included, where he shares how his life was transformed by organ donation while working as a police family liaison officer. The page also includes a sidebar with "Top News Releases" and "Archive News Releases" (listing years from 2016 to 2002), and a "Daily Digest" section with a subscription form.

THE CHURCH OF ENGLAND

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Home > Media Centre > Top News Releases > 2016 > 02 > General Synod backs call to encourage blood and organ donation

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Top News Releases

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Media Centre

General Synod backs call to encourage blood and organ donation

17 February 2016

The General Synod has backed a call for all 16,000 CofE churches to encourage their congregations to consider becoming blood donors or registering as organ donors.

Members voted to approve a motion from Leeds Diocesan Synod put by Father Paul Cartwright, a former police officer and now a priest in Barnsley, South Yorkshire, aimed at increasing the number of blood and organ donors in the UK.

Father Paul told the General Synod of how he had seen lives transformed by organ donation while working as a police family liaison officer supporting families of those seriously injured or killed in road traffic collisions.

He added that after receiving a certificate and gift from the National Blood Service for the number of blood, platelets and plasma donations he made, his life was saved by donated blood products when he was

Archive News Releases

2016	2011	2006	2001
2015	2010	2005	2000
2014	2009	2004	
2013	2008	2003	
2012	2007	2002	

Daily Digest

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Engagement with Islamic Faiths – Amjid Ali



Dialogue on definitions of death



**On the Ethics of Organ Transplantation:
A Catholic Perspective
The report of a working party**



Medical Halacha Conference / UK visit of Rabbi Prof Avraham Steinberg

More than 100 physicians, including many junior doctors, attended a Medical Halacha Conference organised by Drs David Landau and Jacob Opat in November 2011. The main guest visitor, Rabbi Prof Avraham Steinberg took part in all three main symposia, on Organ Donation, End of Life and General themes respectively. He also lectured on Friday morning on Complementary Medicine, and delivered a very well-attended public lecture to a lay audience on Friday night covering “Halachic Issues in Childbirth and the Newborn”. Speakers from the UK included Prof Antony Warrens, Prof Daniel Hochhauser, Prof David Katz and Rabbi Akiva Tatz. There were study sessions on Friday and Sunday mornings about aspects of Jewish Law relating to medicine.

Following this conference Prof Steinberg met with the chairs of BMA and GMC Ethics Committees, together with senior UK medical ethics experts and representatives of the Muslim and Catholic Medical Associations, at the Board of Deputies offices. At this meeting he described how the Israeli End of Life law, known colloquially as the “Steinberg Law”, had been developed. [Later the same day he met with Sir Peter Simpson and Prof Gurch Randhawa from the UK Organ Donation Ethics Committee.](#) Finally he gave a lecture on the topic of “Recent Developments in Jewish Medical Ethics – the Israeli Experience”. In this talk he outlined four examples of how Israeli law on such issues has developed over the years taking cognisance of both medical and halachic concerns.

Following on the success of the conference Drs Landau and Opat have already convened a meeting to arrange a follow – up event in 2012. The intention is that this will include a symposium at a central London venue on the Wednesday evening before the conference in order to attract as wide a medical audience as possible.

Content IV

- Organ donation in multi-ethnic and multi-faith communities – the potential way forward?

Visibility of organ donors....

Minister for Health launches MPs Organ Donation Toolkit with BAME Organ Donor Family



Multi-ethnic and Multi-Faith Donor families becoming more visible – Mainstream media



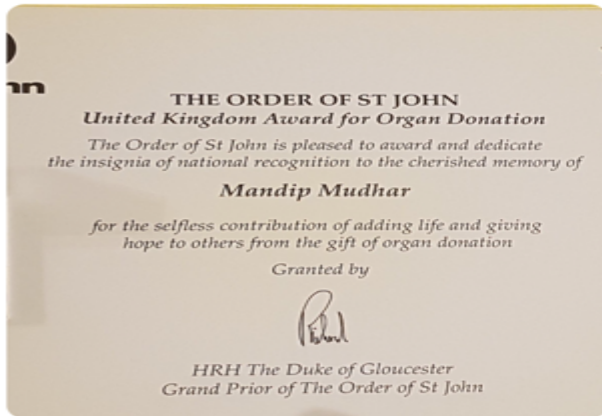
Multi-ethnic and Multi-Faith Donor families becoming more visible - Sport



Multi-ethnic and Multi-Faith Donor families becoming more visible – Ethnic media



HM Queen's Award for Voluntary Services – Mandip Mudhar Memorial Foundation






Community Investment Scheme Launch



Real-life case-studies – multi-lingual

DISCUSSION AND Q&A ON
ORGAN DONATION

SOUTHALL

Gurch Randhawa Sukhdeep Singh Bobby Mudhar Rohit Sagoo


Sunday 9th December 2018 7:30pm onwards

**What are the issues with organ donation?
What does Sikhi say about it? And how can we help?**

Gurch Randhawa: Professor of Diversity in Public Health
Sukhdeep Singh: Sikh educator, Basics of Sikhi
Bobby Mudhar: Chair of Mandip Mudhar Memorial Foundation
Rohit Sagoo: British Sikh Nurses founder

Upstairs Darbar Sahib, Sri Guru Singh Sabha Southall, Park Ave, Southall, UB1 3AG

 **Basics of Sikhi**

Real-life case-studies – multi-lingual



Organ donor family dialogue transcends faith & ethnicity



https://m.facebook.com/story.php?story_fbid=3070369372989339&id=115581954444341&sfnsn=mo

Real-life case-studies – multi-lingual ethnic media



'Donation & Transplantation are 2 sides of the same coin'

Donor opt out to be Max and Keira's Law

A LIFE SAVER
Max's heart
Keira's heart
inside him

CHANGE THE LAW FOR LIFE

A LIFE SAVER
Traagic Keira
has helped
four people

EXCLUSIVE
By JEREMY ARMSTRONG

THE opt-out organ donor legislation championed by the Daily Mirror will be known as Max and Keira's Law.

The Government's change of name honours Max Johnson, 10, and Keira Ball, the girl of nine whose heart saved his life.

Theresa May told the Tory conference last year that the legislation was to be known as Max's Law.

But Max announced he wanted his hero's name added - and Keira's mum Louisa wrote to the PM with the same suggestion.

Both children's families have now been told by Health Minister Jackie Doyle-Priest of the move.

Louisa said: "This is fantastic news. It's so important to our family that names will save a further 700 lives a year. The Government predicts."

Louisa said: "That would be amazing. I'm so passionate about spreading the word on donation."

She said her children Bradley, nine, Katelyn, 13, and Keely, 14, are "extremely excited" that their sister's name will "live on for ever."

The Organ Donation (Deemed Consent) Bill 2017-19 will mean each capable adult is presumed to be an organ donor when they die unless they opt out.

It had been set for the formality of committee stage in the Lords this week.

Then it would have gone for royal assent to become law.

But two amendments by a Tory and a DUP peer mean it will now go to committee early next year. Its sponsor, Labour's Lord Hunt of Kings Heath, said: "I still think the Bill is in good shape and I hope there will be no need to refer it back to the Commons."

Mrs May said yesterday: "We know more people are willing to consider organ donation than are registered donors. That is why we are changing the law to make it easier to donate - by presuming consent unless people opt out."

"I was reminded of the importance of this when Max visited me at No10."

"He has told of his gratitude to Keira and her family for saving his life."

"Her parents' courage and strength is inspiring. It's fitting we reneise this important law so we can pay tribute to Keira as well as Max, to ensure her life is never forgotten."

Jeremy Armstrong is a writer for the Daily Mirror. He can be contacted on Twitter @jeremyarmstrong.

Change the law for Max

PELA Front page in 2017

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Jeremy Armstrong is a writer for the Daily Mirror. He can be contacted on Twitter @jeremyarmstrong.

VOICE OF MIRROR: PAGE 6

Developing Organ Donation public engagement in the UK

- **What is the message? Who are the messengers?**

Donors, donor families, recipients, community leaders, faith leaders, NHS staff.....

NHSBT funded feasibility study of primary care and Organ Donor Registration – Pedder-Jones C, Papadopoulos C, Randhawa G & Asghar Z (2018) Research protocol: general practice organ donation intervention—a feasibility study. (GPOD). Pilot and Feasibility Studies. 4:171
<https://doi.org/10.1186/s40814-018-0362-9>

- **Take an Intercultural approach NOT a multicultural approach**

Europe's population change 2007-2050

