Organ Donation Research Programme – Impact Case Study

‘Stay Connected’

Professor Gurch Randhawa

Director, Institute for Health Research

@gurchrandhawa

University of Bedfordshire

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

MCB

HFB

SEVENTH-DAY ADVENTIST CHURCH

EVANGELICAL TRUTH AND APOSTOLIC ORDER

The Bishops' Conference of Scotland

NETWORK OF SIKH ORGANISATIONS
UNITY IS STRENGTH

BSCF
BRITISH SIKH CONSULTATIVE FORUM

THE MUSLIM COLLEGE • LONDON UNITED KINGDOM

The Buddhist Society

RAMADHAN FOUNDATION
WORKING FOR MUSLIM UNITY

Church of Scotland

Our approach to developing research impact case-study

- **Define research problem**
- **Articulate underpinning research**
- **Evidence research impact to policy and practice**

Our approach to developing research impact case-study

- **Define research problem**

What is organ donation?

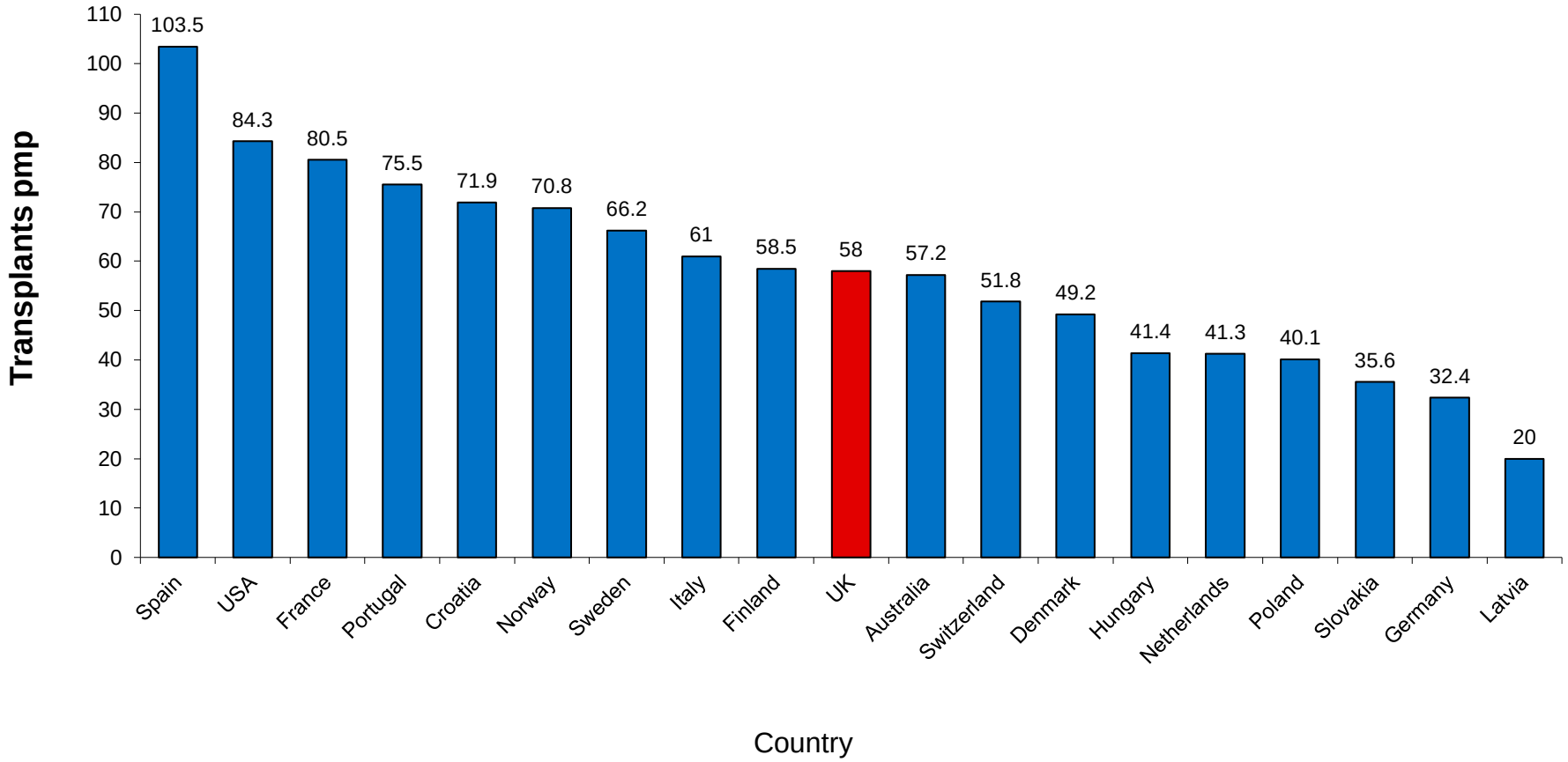
Organ donation is the process of giving an organ to someone who needs a transplant because their life is seriously affected by a failed organ.

Most organ donation occurs after death (**deceased donation**) although organ donation is possible from living donors (**living donation**).

NHS Blood and Transplant

Deceased donor transplant rates

Total deceased donor transplant rates for Europe, Australia and the USA, 2017

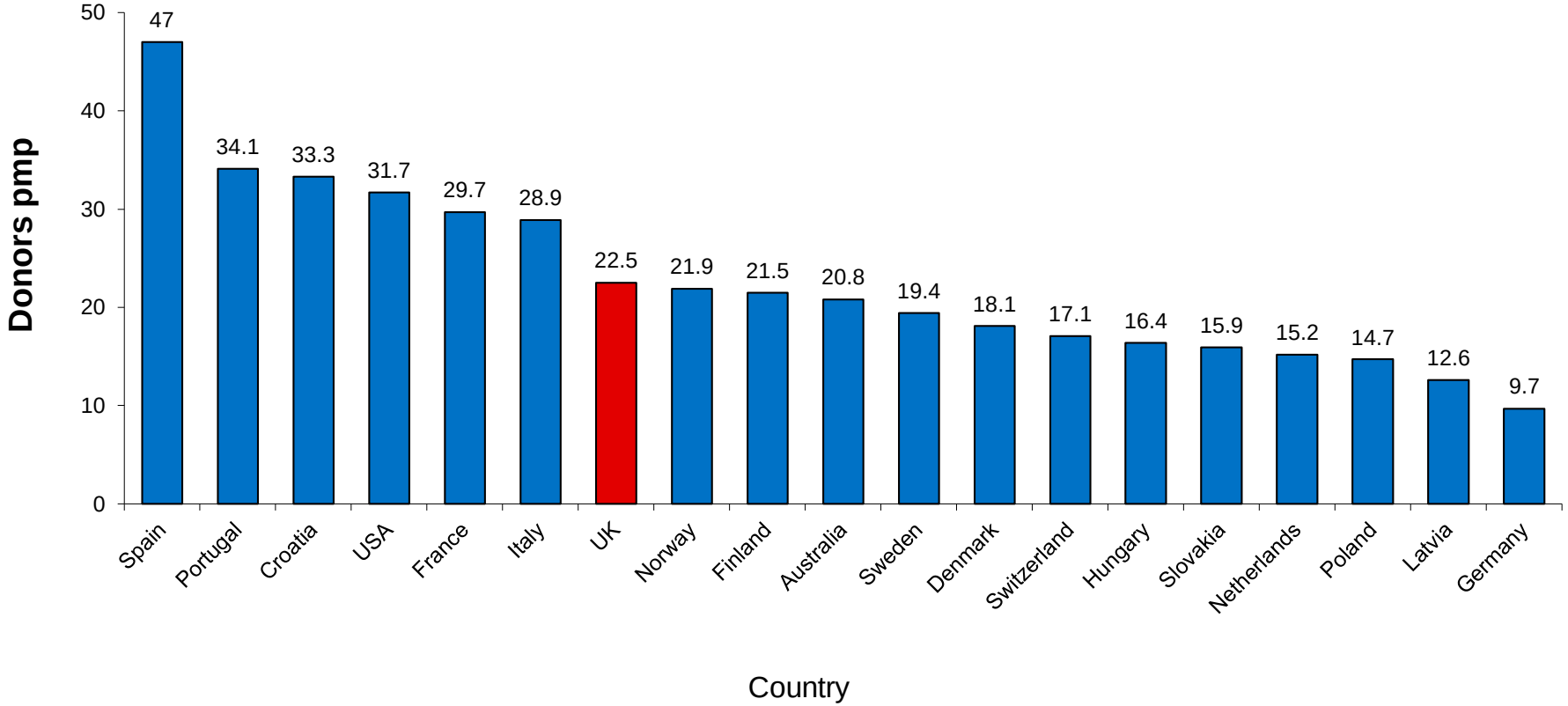


Source: Council of Europe – Transplant Newsletter

NHS Blood and Transplant

Deceased donor rates

Deceased organ donor rates for Europe, Australia and the USA, 2017

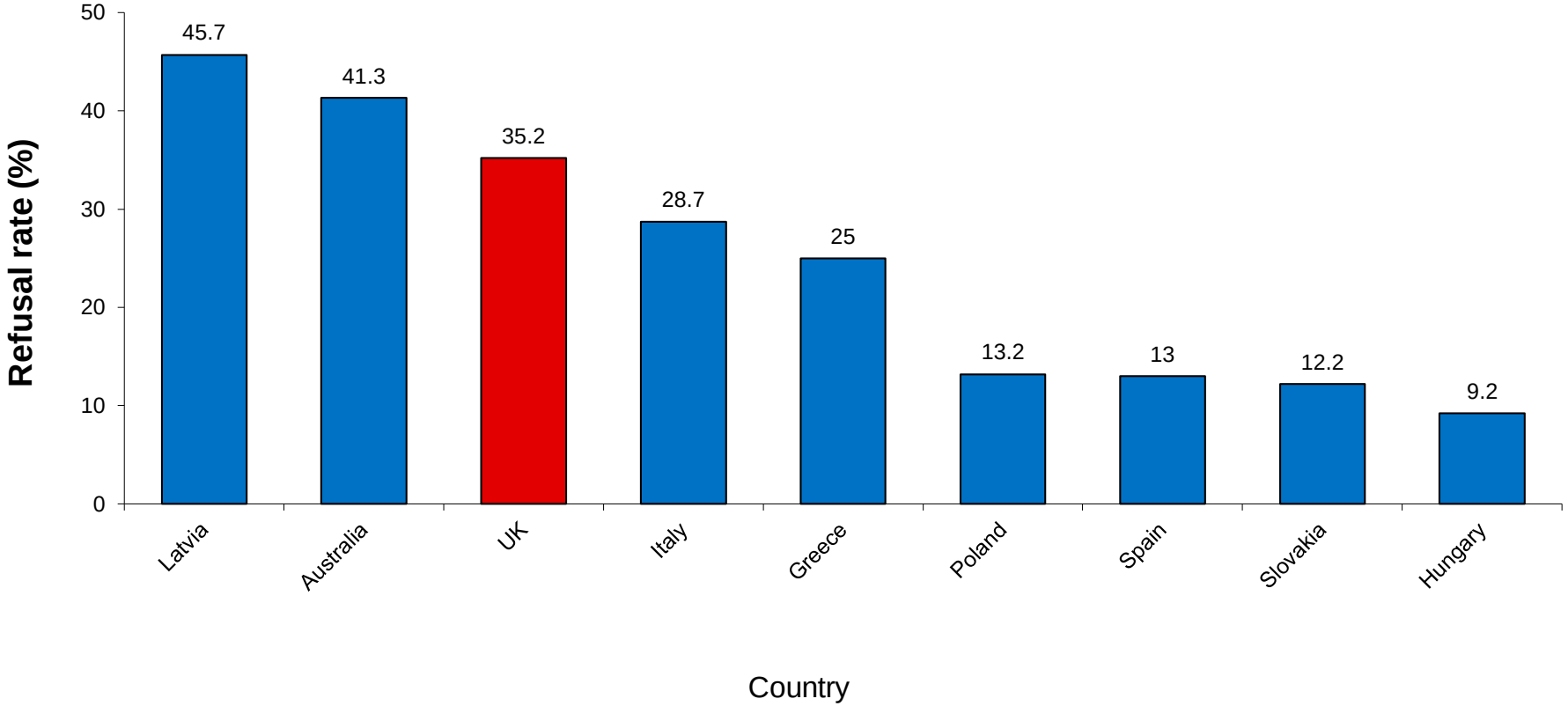


Source: Council of Europe – Transplant Newsletter

NHS Blood and Transplant

Family refusal rates

Refusal rate for Europe and Australia, 2017



Note – limited international data available on family refusal rates

Source: Council of Europe – Transplant Newsletter

Organ donation in the UK

University of Bedfordshire

Over 6,500 people waiting for a transplant, on average 3 people a day die waiting for a transplant in the UK

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 35% versus White families 69.0%

University of Bedfordshire

Why is organ donation important to BAME communities ?

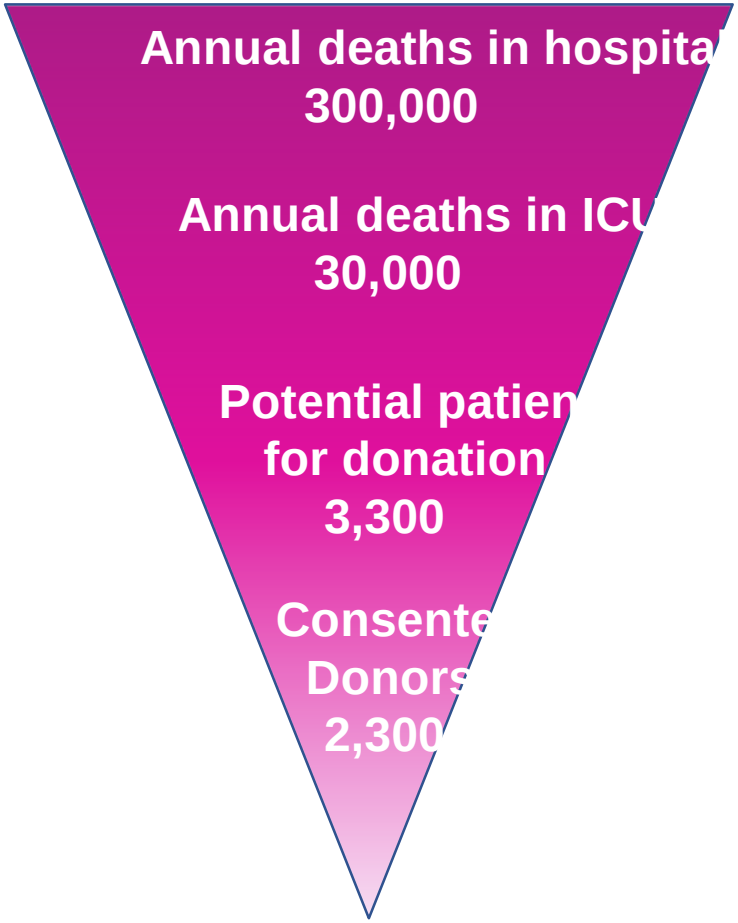
Caucasian patients wait ~ 640 days for a kidney transplant

Asian patients wait on average 830 days (about 30% longer)

Black patients wait on average 965 days (about 50% longer)

Yes I donate
ORGAN DONATION

There are a shortage of organs available for transplantation



The chance of someone being suitable as an organ donor if they die is ~ 1%

So nationally there are a limited number of potential organ donors

And therefore every consent refused by families has a significant impact

Our approach to developing research impact case-study

- **Articulate underpinning research**

University of Bedfordshire

Solving inequalities in organ donation 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
- (Randhawa, 2000)

What does our research say?

University of Bedfordshire

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)

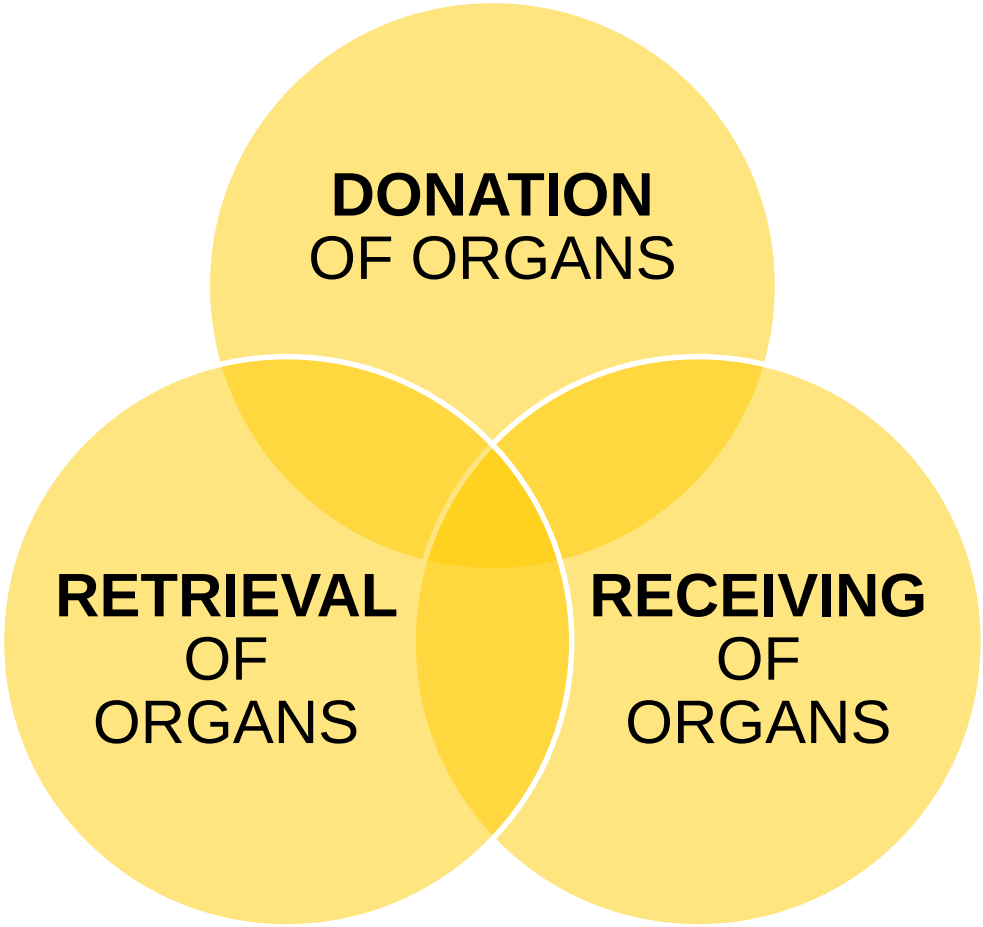
University of Bedfordshire

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)

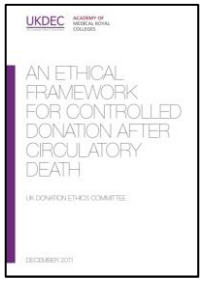
Public Engagement & Organ Donation Taxonomy

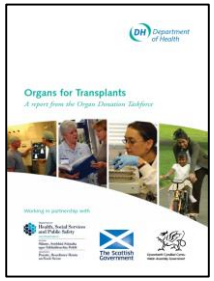
(Randhawa G (2011) Organ donation and transplantation – meeting the needs of a multi-ethnic and multi-faith UK population. In: Farrell A, Price D, Quigley M. Organ Shortage: Principles Pragmatism and Practice Cambridge University Press.)



Our approach to developing research impact case-study

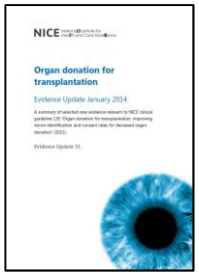
- **Evidence research impact to policy and practice**


UKDEC
AN ETHICAL FRAMEWORK FOR CONTROLLED DONATION AFTER CIRCULATORY DEATH
UK DONATION ETHICS COMMITTEE
DECEMBER 2011


Department of Health
Organs for Transplants
A report from the Organ Donation Taskforce
The Scottish Government

The potential impact of an opt out system for organ donation in the UK
An independent report from the Organ Donation Taskforce

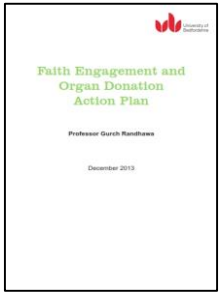
HOUSE OF LORDS
European Union Committee
17th Report of Session 2007–08
Increasing the supply of donor organs within the European Union
Volume I: Report


NICE
Organ donation for transplantation
Evidence Update January 2014

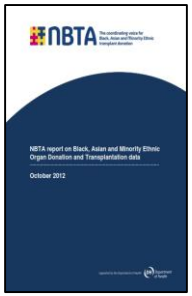
cerdyn rhoddwr
donor card
NHS
Cofrestr Rhoddwyr
NHS Organ Don
GIG

NHS
National Institute for Health and Clinical Excellence
Organ donation for transplantation: improving donor identification and consent rates for deceased organ donation
Issued: December 2011

NBTA
a vision for change
a voice for the future
Strategic Plan 2012-13 » 2014-15 | 4 July 2012
Department of Health


Faith Engagement and Organ Donation Action Plan
Professor Gurch Randhawa
December 2013

NHS
Blood and Transplant
NHS Blood and Transplant response to publication of the Faith Engagement and Organ Donation Action Plan
Sally Johnson
Director of Organ Donation and Transplantation, NHSBT
December 2013

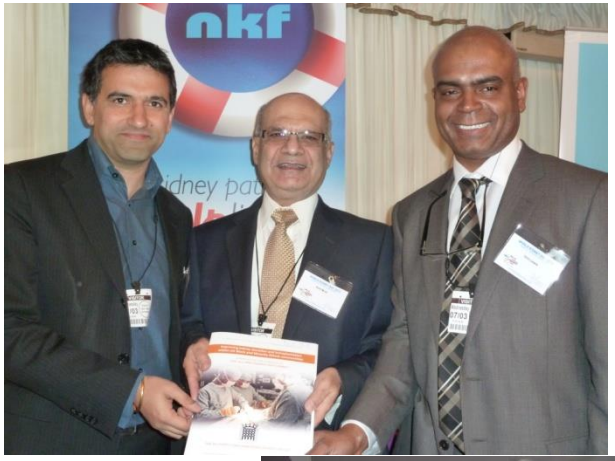

NBTA
NBTA report on Black, Asian and Minority Ethnic Organ Donation and Transplantation data
October 2012

NHS Organ Donor Card
Yes I donate

Professor GURCH RANDHAWA
University of Bedfordshire
BBC NEWS
bbc.co.uk/news

PRESS
08:58

BBC


okf

donor card
NHS
NHS Organ Donor Register

NHS
Blood and Transplant
1st National Donation Congress
7th & 8th March 2012

healthcarenetwork
Insight, reports and data for NHS innovators

Transplanting a culture of organ donation

Black and minority ethnic groups are under-represented on the organ donation register, but face to face events can help

Ben Whitelaw
Guardian Professional, Tuesday 12 July 2011 09.00 BST

Prof Gurch Randhawa at a conference to increase organ donation awareness amongst the Hindu community. Photograph: BAPS Sanstha UK

Impact case study – Metrics….

2014/15	2018/19
6.3% of new ODR registrations were ethnicity given were BAME	7.1% of new ODR registrations were ethnicity given were BAME
BAME consent rate = 36%	BAME consent rate = 41.7%
BAME waiting list = 1957 (28.6% of list)	BAME waiting list = 1883 (31.4% of list)
80 deceased donors (6.2% of deceased donors)	121 deceased donors (7.6% of deceased donors)
159 BAME living donors (14.6% of living donors)	149 living donors (14.3% of living donors)
892 BAME organ transplants (20.3% of all transplants)	1,148 BAME organ transplants (23.2% of all transplants)

donor card
NHS
NHS Organ Donor Register
Making organ donation usual
Transplants save lives
Diversity and Complexity
Essex Black & Ethnic Minority Research C
The Knights Way Centre, 32A Knights Way, Brentwood-Essex, CM13
BEM Organ Donation Awareness Works
donorcard