

# Increasing awareness about organ donation in the South Asian community and reducing treatment costs



**PRESENTED BY: DR. AGIMOL PRADEEP**

# Clinical Service Background

- Renal and Transplant Nursing Background
- Challenged by Asian renal failure patients on disparity in organ allocation and blaming the NHS
- Reduced transplant rate and increased treatment cost
- Continued commitment to NHS and for the delivery of care to people living with organ failure and their carers
- Wanting to provide the best available and quality treatment option to all organ failed patients



# Incidence of CKD In Asians

- Asians are **three to four times** more likely to develop Chronic Kidney Disease than whites.
- This rises to **eight times** for older Asians
- **Diabetes five times** the rate of the white population
- **Hypertension** is twice the rate of the white population.



# Clinical Service Background

Less than 2% on the ODR while representing more than 15% on transplant waiting list

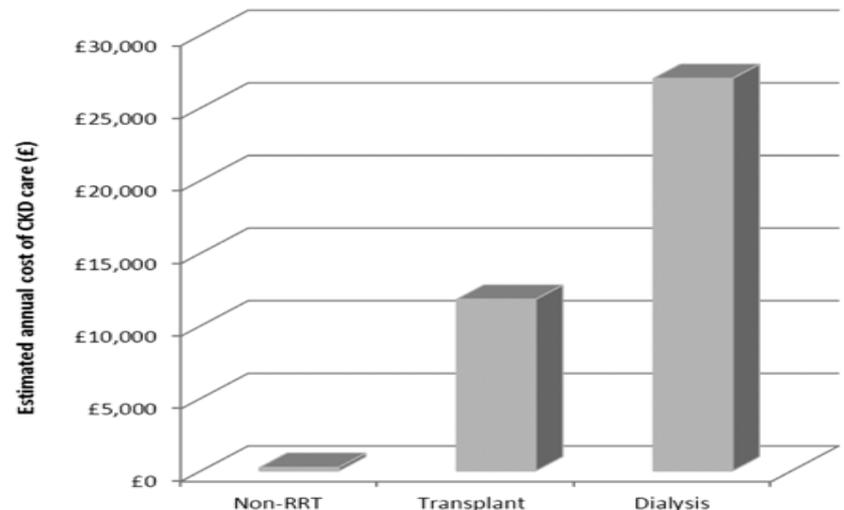
## Kidney Statistics

Demographic characteristics of deceased kidney donors and transplant recipients over the past 5 years

Financial year	Number of donors		Number of transplants		Patients on the active transplant	
	White	Asian	White	Asian	White	Asian
2010/2011	917	12	1305	230	4954	1099
2011/2012	988	15	1425	215	4673	1114
2012/2013	1097	19	1473	260	4386	1074
2013/2014	1197	39	2783	400	4945	1123
2014/2015	1092	30	2614	417	4852	1081

# Why is it important to promote the organ donation message to enable more transplant opportunities

1. Improved Clinical Outcomes
2. Increased Survival Rate
3. Improves long term health
4. Reduces the risk of dying from kidney disease *(UK Renal Registry Report 2011: p47)*
5. Better Quality of Life
6. Cost effective treatment *(Kerr et al. 2012)*



*Estimated annual cost of direct CKD care, RRT and non-RRT patients. (adapted from Kerr et al. 2012)*



With the strong evidence explained in the above slides, researcher completed a doctoral study (2012-2015) to find out the reasons of the scarcity of South Asian organ donors and implemented education intervention to increase the organ donor rate from the South Asians.

Doctoral study explained in Slides 7-12



# **Doctoral study completed in two phases**

## **Methods**

### **Phase one:**

- Questionnaire survey (from 907 South Asian participants) to capture attitudes towards organ donation and to understand South Asian beliefs, barriers and awareness of organ donation - translated into three key languages (Urdu, Hindi and Bengali)
- Interviews with 10 individuals who declined to join the organ donor register (ODR)

### **Phase two:**

Implementation of education approach

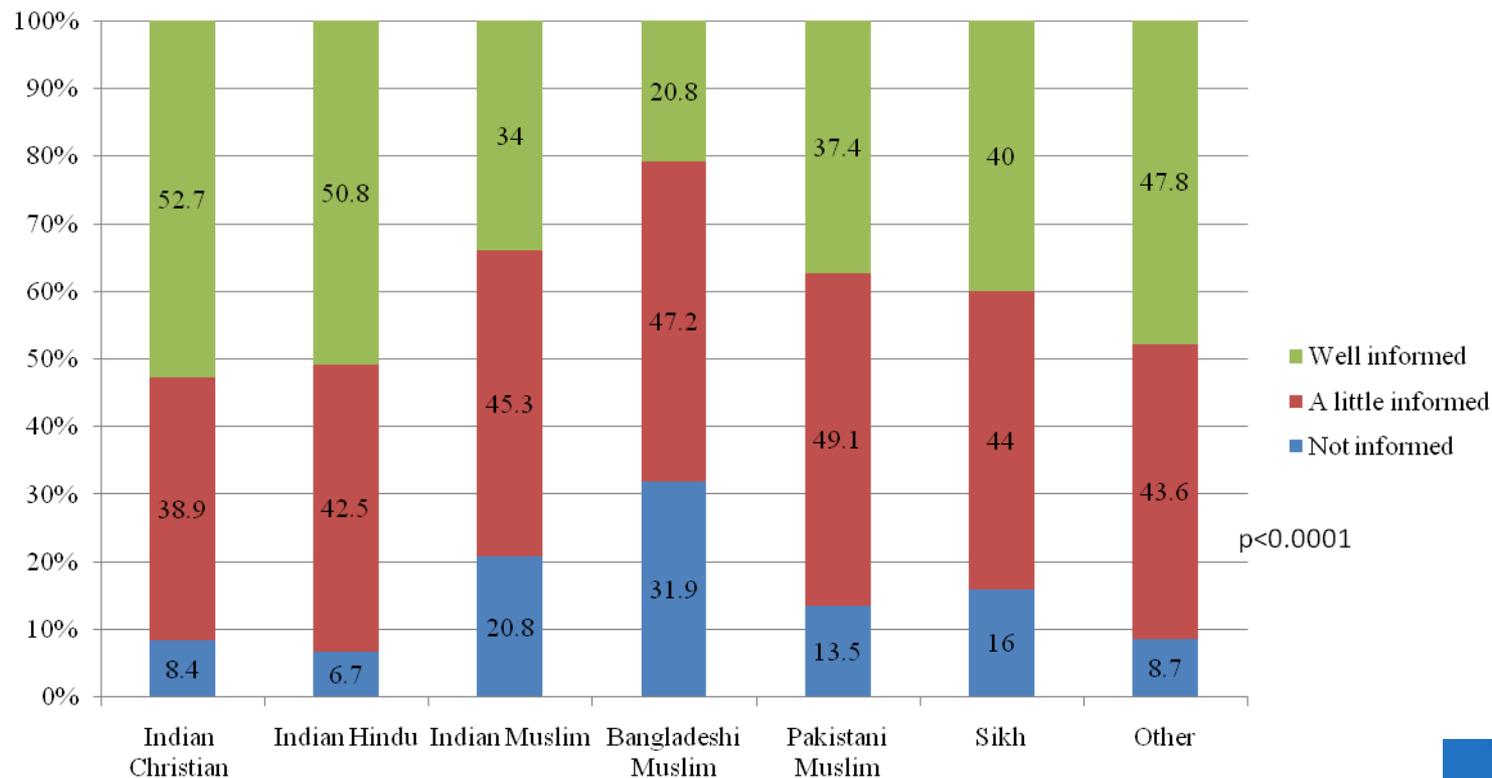
- Peer Education sessions in the community

# Results from the Doctoral study

- Only 45% of respondents felt well informed about registering as a kidney donor or donation in general.
- 55% of participants did not know enough about organ donor registration and yet more than 88% had higher education.
- There is a great need for more knowledge and education to increase awareness about kidney donation & **religious clarifications**.
- Misconceptions, such as when agreeing to donate organs they may not receive active medical treatment or misused for research purpose.
- Need to concentrate on younger generation to clarify their mistrust in medical team/misuse of organ

## Highly Educated Lacking Awareness

Knowledge about registering for organ donation was significantly different between ethnicities, religions and between communities ( $p < 0.0001$  in all cases). Over 54% of the participants did not feel well informed about registering as a kidney donor.



## Evidence for the need for education

Questions	Yes/Agree	Not sure	No/Disagree
Agree with Organ Donation	44%	39%	17%
Opt Out	57%	25%	18%
Live donation	60%	32%	8%

# Result of Peer Education in the Community

More than 3000 South Asian people registered as new ODR from 302 peer education sessions.



More than 3000 individuals joined the ODR



302 Events



TV documentaries/ Youtube



Radio talks



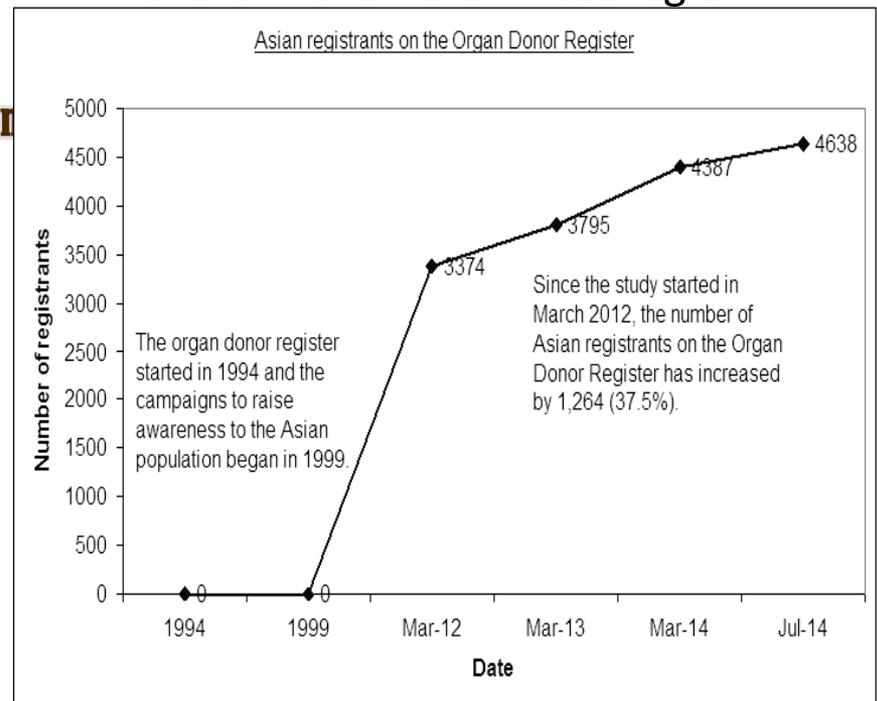
Presented the study in MDT meetings including European conference



Best Nurse by Brith Malayali (2013) & British Journal of Nursing (2015)

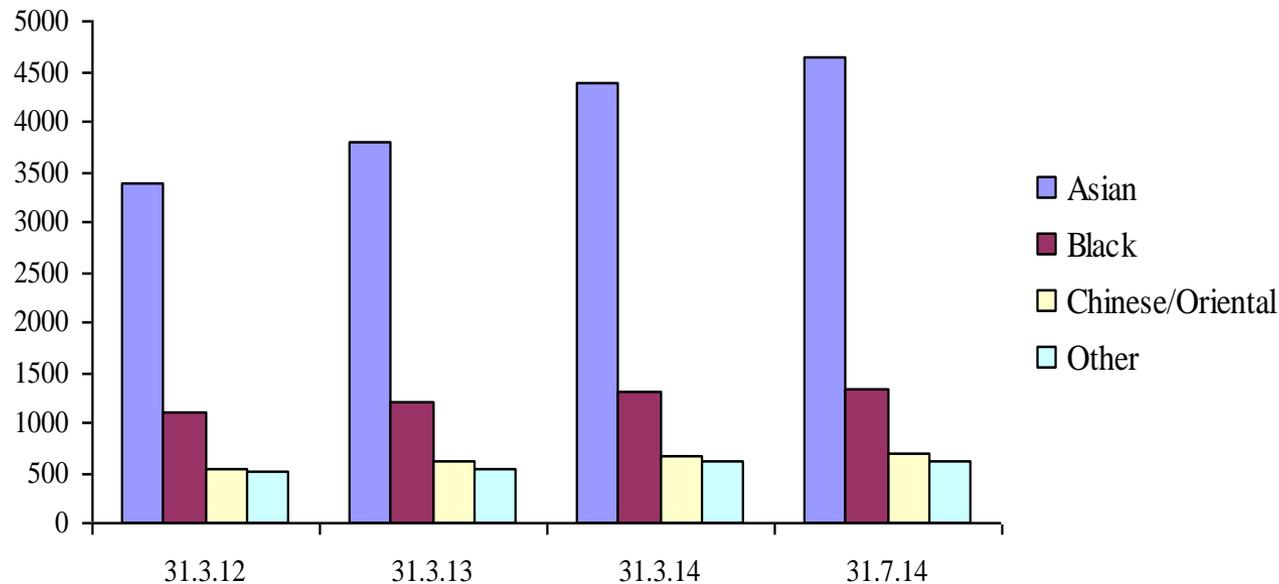
## North West ethnicity ODR data UK

Since year 1999 till 2012, ODR data shown 3374 Asians. But current campaign has increased the number of Asians on ODR by a further 37.5% in just 24 months in the North West region.



# North West ethnicity ODR data for the UK (2014)

Impact from the study proven that, whilst there has been a dramatic increase in the number of Asian people joining the ODR other BAME groups have not experienced the same intensive activity, confirming that the intervention of the education approach had significantly directly influenced the number of ODR Asian registrants.



**Following the successful completion of the Doctoral study (2012-2015), researcher commenced the Economic Assessment course in (2015) to identify and assess the cost implications to execute the below mentioned two interventions.**

1. By concentrating more on the younger generation in the High Schools and Universities (as only 45% of the highly educated participants in the study were aware about the organ donor registration)
2. South Asian community to increase the knowledge on organ donation topic.

**Slide 14-24 will explain the proposal of this Economic Assessment**

# Perceptions of Economic Assessment

- Presumption of ‘high level’ process and it is done by only finance experts
- Economic evaluations felt far removed from day to day experience of a Nurse
- Frustrated that many new policies and publications coming in with suggestions to increase BAME donors but not reflecting how they have been implemented and the end results, but would become the basis for both the commissioning and prioritisation of service provision at local & national level

# The opportunity

- Participation in a unique, accredited programme of supportive learning
- Opportunity to save more lives
- Potential for significant professional and service development
- Personal awareness and insight
- Able to demonstrate and provide the evidence on the positive impact from my own work



# Organ Donation Education Pathway to outcomes

## Direct Input

- 1x WTE Band 8 Educator with Transplant and cultural experience
- 0.4x WTE Band 3 Administrative support
- Office space
- Education materials (including pre and post education questionnaires) and electronic equipment



# Groups Targeted

## **For Intervention**

Obtain the permission from community and religious leaders, also schools' or universities' head teachers to do a session on organ donation awareness

Make a contract to do a yearly session for the coming 5 years

Provide the opportunity for the attendees and students to join the ODR following the session

Measure the impact of the education by monitoring the ODR register by using the coded forms

## **For partnership**

NHS Blood and Transplant

Community, Religious Leaders and Schools

Local authorities

Funding partner

## **For Delivery**

Educator (Who is an expert on organ donation, allocation and transplantation along with knowledge on religious and cultural factors)

Community, Schools/University premises

Materials supplied by NHSBT

Materials for power point presentation



# Activities and Outputs

- Community and School Education
- Educator management plan
- Keeping a record on how many educated, and outcomes
- Identifying key individuals (Community and Religious leaders, Teachers, Students, Support staff etc) from Schools and Universities to act as link workers
- Performing a pre and post education session knowledge questionnaire to measure the impact



# Connection between the organ donor register and increased deceased donor rate

- In the UK we follow opt in system for organ donation, and medical team will approach the family for the consent
- So, the dilemma for families and the barrier to organ donation is their own uncertainty about what the deceased would have wanted to do (Sque et al. 2005)
- Only 31% (3 out of 10) of families in England willing for donation to go ahead if they are unaware of their loved one's decision to donate (NHSBT 2012).
- But 60% (6 out of 10) families approached about organ donation will give their agreement for donation if the potential donor is a registered organ donor (NHSBT 2012).
- Studies among the next of kin of organ donors shown that, they are more likely to grant permission for organ recovery if the deceased had indicated during their lifetime a willingness to become an organ donor (DeJong et al. 1998; Siminoff et al. 2001)

## Outcomes

- Increased knowledge among the South Asian community and younger generation and rise in potential organ donors
- Increased consent rate for organ donation as families are more aware about the terminologies
- Increased transplant opportunities
- NHS able to provide the best quality treatment option for the organ failed patients with more transplant opportunities secondary to more families giving consent for organ donation
- Reduced costs attached to managing the organ failed patients eg; Dialysis dependent patient become free from dialysis, insulin dependent diabetic patients free from injecting insulin etc

# Key benefits

- Increased awareness on organ donation topic among young people and South Asian community, will improve the organ donation rate in the future
- Increased organ donation rate will save more lives through transplant opportunity
- Ethnic matched donors to recipient have better survival rate (Devlin 1993)
- Cost benefit in the NHS economy
- Able to provide the best available treatment option for organ failed patients i.e. Transplants
- Developing positive rapport with hard to reach community and increasing trust in the medical team
- Reports (digital and social) about this initiative will spread the Gift of Life message

# Cost for the organ donation education intervention implementation in the community/schools

*(Costs at 2015 values)*

Band 8 staff 1WTE      £52675

**(Recurring annual cost)**

Band 3 staff WTE 0.4 £8805

(To assist with net working and pre and post questionnaire survey)

**(Recurring annual cost)**

Travel cost                      £8,000

**(Recurring annual cost)**

Telephone + Wifi              £600/yr

(£50x12)

**(Recurring annual cost)**

Laptop x2 + Projector    (£400x2)+£300 = £1,100

**(One off cost)**

**Total Cost: £ 71,180**

# Economic savings to NHS through implementing Organ Donation education intervention

As researcher is a renal specialist nurse and with kidney being the most frequently transplanted organ (Matesanz et al. 2009). This proposal is looking from the kidney perspective only even though one potential donor could donate up to 9 organs,. One deceased donor from kidney perspective will save £48,200 (<http://www.kidney.org.uk/> 2010) which will be adjusted to **£55061 at 2015 value according to Treasury Guidance i.e. 2.5% increase/ year.**

The transplantation of four kidneys from two donors in 12 months alone would cover the costs of the proposed programme. However that only accounts for the costs of dialysis, it doesn't take into account other benefits which might include

- a) The increased potential of the recipients to contribute to the economy,
- b) The benefits of the transplantation of other organs from these donors
- c) Wider potential benefits from the education programme such as live donations, as evidenced in Doctoral study (Pradeep, 2015 )
- d) Engaging with community with health education topic and its impact is not monetised here

Networking among “hard to reach” community is a challenge faced by NHS for decades. Intervention contributes to addressing this challenge, but is not monetised here

Clarifying the myths and developing trust in the community towards medical team

# Challenges

- Supporting or funding organisation
- Networking with key staff
- Data collection
- Data cleanse to ensure accuracy
- Costs identified for each location
- Results – XL spreadsheets for clarity



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*This case study was undertaken by **Agimol Pradeep**, when she was a Transplant Recipient Co-ordinator, Central Manchester Hospitals and completed in **December 2015**.*

*Agimol successfully completed a collaborative learning programme designed to empower nurses to understand, generate and use economic evidence to continuously transform care. The programme was delivered by the Royal College of Nursing and the Office for Public Management, funded by the Burdett Trust for Nursing and endorsed by the Institute of Leadership and Management.*

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