

# Diversity in organ donation within Scotland - improving awareness amongst the South Asian ethnic minority communities.

## Introduction

There is an imbalance between the need for organ transplants in South Asian communities in Scotland and the availability of matching organs, resulting in healthcare inequalities. In 2014, Kidney Research UK, funded initially for 2 years by Scottish Government, established the volunteer Peer Educator (PE) initiative, raising awareness in Glasgow, later in Edinburgh, on kidney health/disease, and the importance of organ donation within the ethnic minority South Asian communities. More culturally appropriate education and awareness were required for people within the South Asian communities to understand health conditions and maintain good self-care. Through their work the volunteers aimed to prevent further decline of people's ill health, and to improve understanding about the importance of organ donation to save lives within these communities.

## Methods

Kidney Research UK recruited volunteers from the target communities- predominately the Sikh, Hindu, Muslim, and cultural groups who were then trained and educated to disseminate information on kidney health/disease and deceased and living organ donation. The 12 PEs attended community events, schools, hospitals, cultural and religious establishments to educate and raise awareness and signing people onto the organ donor register (ODR).

With the recent change of Scottish "opt-out" legislation in March 2021 and due to the pandemic, it meant it was even more imperative that people were aware that their faith and beliefs can be recorded on the ODR. Working in partnership with NHS Blood and Transplant, Scottish Government, community members, and senior faith leaders, we updated resources and information for people to understand all aspects of donation from law change to faith issues. Using digital technology, short films on organ donation were produced with the support of faith leaders and community members, which were shared online and social media.

Despite the pandemic, innovative solutions were deployed to ensure information sharing with local communities and NHS staff, which helped to inform healthcare workers about faith and cultural needs of diverse communities. The project used digital platforms to host 13 webinars within the Muslim, Hindu and Sikh communities and Interfaith Scotland reaching **1393** people online. Engagement with local community radio stations (Awaz FM and Radio Ramadan) and digital magazine, Asian voices, aided the dissemination of information. We engaged and raised awareness with MSPs to encourage conversations about organ donation within constituencies and in Parliament.

Our PEs are amazing and enthusiastic volunteers with three original members, in their 70s, who remain highly active despite their busy lives and other commitments.

## Outcomes and learning

1. An appreciation of the clinical and societal imperative of organ donation
2. Recognition of the benefits of online and digital platforms maximising reach and impact.
3. Need for continued collaboration and cooperation across multiple agencies to empower communities to make the right choice with regards to organ donation.
4. Appreciation of and examples of effective ethnic minority community engagement strategies to reduce health inequalities

## Organisations involved

- Bushra Riaz - Policy lead (Scotland), Kidney Research UK
- Linda White - Scottish Government, Policy manager
- Dr Radha Sundaram - NHS BAME Organ donation lead
- Neerja Jain - Health equalities programme manager, Kidney Research UK
- Alison Railton - Head of policy and external affairs, Kidney Research UK

Despite the challenges of the pandemic over the last 2 years, it is reassuring to see that there has been an increase in the proportion of opt-in registrations from minority ethnic communities added to the NHS Organ Donor Register (ODR) over the past 5 years; from 6.8% of opt-ins with ethnicity reported in 2016/17 up to 9.2% in 2020/21. **(NHSBT annual report 2021)** Building and maintaining trust and good relationships with faith and community leaders has been key to the impact of the peer educator's work. Thanks hugely to the peer educators' passion and tenacity, evaluation from Scottish Government awareness raising campaigns have shown that there has been a 10% increase and more people from these communities are now aware about the choices they have around organ and tissue donation and have the information they need to make an informed decision. This will help to reduce waiting times for organ transplant and reduce the health inequalities.

## Results

Now in its  
**9th**  
year of  
funding

Volunteers have  
participated in

**over  
180 events**

Engaged with

**10,341 people**

**Signed over  
1,150 people** to the  
NHS ODR

With one person saving up to

**nine lives!**

This has resulted in  
positive outcomes  
and discussions  
within communities.

