Evaluation of the Kidney Research UK Peer Educator Programme to improve understanding of organ donation amongst Black and minority ethnic communities and to increase the number of Black and minority ethnic organ donors

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With

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**Background:**

Black and minority ethnic communities are disproportionately affected by inequalities in transplant services in the UK. They are at greater risk of developing organ failure, less likely to be organ donors and wait longer for transplants (Randhawa, 2011).

Prevalence of Type 2 diabetes is up to 6 times higher among South Asian and African Caribbean communities than in the white population (Riste et al 2001; Forouhi et al, 2006). Viral hepatitis – hepatitis B and C – is also more prevalent in the South Asian population, leading to increased likelihood of liver damage and liver failure. South Asians comprise over 10% of the liver transplant list (Randhawa, 2011).

People of South Asian origin represent 15% of those waiting for a kidney transplant even though they comprise only 4% of the general population. For African-Caribbean patients the figures are over 7% on the waiting list compared to 2% of the UK population. Conversely, only 2.1% of people who donate kidneys after death are South Asian and 1.2% African-Caribbean (Randhawa, 2011). Only 1% of people registered on the Organ Donor Register are South Asian and 0.3% are African-Caribbean (Rudge et al, 2007).

South Asian and African-Caribbean people wait on average twice as long as white people for a kidney transplant (Randhawa, 2011). While white patients wait on average 719 days, Asian patients wait 1368 days and Black people wait 1419 days (Rudge et al, 2007).

The problem is compounded by the fact that relatives from Black and minority ethnic communities are less likely to consent to donation following bereavement (Murphy and Counter, 2009; Barber et al, 2006).

**Policy Interventions:**

A number of studies have identified a range of barriers that prevent people from Black and minority ethnic communities registering as organ donors. These include: religious beliefs (Davies and Randhawa, 2006); fear that organs might be removed prior to death (Alkhawari et al, 2005); fear that medical treatment might be withheld if the person is a donor (Alkhawari et al, 2005); and a fatalistic attitude towards serious illness (Alkhawari et al, 2005). Randhawa (2011) has added to this a lack of awareness amongst minority ethnic communities about the specific needs of their communities for organs. Interestingly enough, Randhawa (2011) has also pointed out that none of the major religions object to organ donation in principle, although in some there are varying schools of thought.

The Organ Donation Taskforce (Department of Health, 2008) concluded that increasing the number of all organ donors should be an urgent requirement and that there should be a specific focus on Black and minority ethnic communities. In recent years the Department of Health and NHS Blood and Transplant have produced a range of educational materials (including leaflets, posters and videos) in the main South Asian languages to increase awareness of transplant related issues, as well as launching some specific Black and minority ethnic campaigns. Materials have also been produced setting out the position of each religion regarding organ donation (Randhawa, 2011).
Randhawa (2011) suggests that interventions to reduce inequalities should take a two-pronged approach:

- Preventative strategies, raising awareness about the causes of disease, healthy lifestyle choices and the importance of screening to decrease the number of minority ethnic patients requiring a transplant in the long term; and
- Increasing the number of organ donors from minority ethnic groups in the short term.

There are indications from pilot work in the UK and research overseas involving minority ethnic groups that appeals for African-Caribbean and South Asian donors may be more effectively communicated by employing a grassroots, community networking approach (Morgan et al, 2010). Randhawa (2011) argues that evaluation of such community based interventions should be a priority. This paper seeks to make a contribution to the evaluation of such programmes.

The ABLE programme – Kidney Research UK

Kidney Research UK has recently launched the ABLE (A better life through education and empowerment) programme. As part of this a Peer Educator programme was piloted in Harrow (Middlesex) and subsequently rolled out to Hounslow, Lewisham and Lambeth. The programme aimed to both raise awareness of the issues surrounding organ donation for Black and minority ethnic communities and to increase the numbers of Black and minority ethnic people on the Organ Donor Register.

Peer Educators for the pilot were drawn from local Black and minority ethnic communities and included: a middle aged Indian Hindu male; a middle aged Somali Muslim male; a middle aged Nigerian Christian female; a middle aged Kenyan Muslim female; a middle aged Hindu female; a middle aged Gujurati Jain and an older Indian Hindu female. The Peer Educators were primarily drawn from a pool of Health Trainers who were employed by NHS Harrow. They were given two days training which detailed the extent of the problem faced by Black and minority ethnic groups in relation to both their high risk of requiring donated organs and the severe shortage of Black and minority ethnic donors. The training was accredited at level three with the Open College Network. They were also given additional training on presentation skills.

The Peer Educator programme involves education and awareness raising which is directed at Black and minority ethnic groups. A range of specific venues and community events are targeted in order to maximize engagement with Black and minority ethnic communities. An example of the type of events attended by the Peer Educators is set out in box 1.

Generally, the Peer Educator programme takes two forms: in the larger settings a stand, which is typically staffed by two Peer Educators, is positioned in a prominent position such as an entrance foyer. Posters are also displayed to attract people to the stand. Additionally, and usually in smaller settings, presentations may be given to small groups. During both the large and smaller events, the programme seeks to provide relevant information and attempts to address misconceptions about donation whilst at the same time encouraging members of BME communities to register on the Organ Donor Register (facilities for registering on the Organ Donor Register are provided by the Peer Educators at the events). The team have developed a quiz which they use as an ice breaker and as a way of opening up a discussion about organ donation.
Box 1: Examples of events run by the Peer Educators

Asian Bridal Show

This event in Wembley Stadium in Middlesex was attended by over 20,000 people. The Peer Educators staffed a stand at the event. The Peer Educators also approached people directly and engaged them in conversations about their knowledge of organ donation.

Yeading Library (Hayes)

The Peer Educators positioned a stand near the entrance of the library. The Peers found that people had time to speak to them as they entered or exited the building.

Oshwal Elderly Welfare Association – Yoga group:

This setting involved a Yoga group for the over 50’s. It took place in a room where the Yoga group usually meets. The Peer Educators gave a presentation in Gujarati. The group of 14 people gave very positive feedback to the session, which was initially planned to last 15 minutes but went on for 30 minutes. This presentation involved a high degree of audience involvement with two members of the audience describing their direct experience of kidney disease.

The evaluation framework

The evaluation was completed by a team of researchers from the School of Social Work at the University of Central Lancashire with funding obtained by PRIAE (the Policy Research Institute for Ageing and Ethnicity) via the Department of Health.

The evaluation took place over two phases. Phase one took place between January and May 2010 and focused on the pilot programme being developed in Harrow, seeking to identify the appropriateness of the model as a way of engaging Black and minority ethnic communities and the lessons that should be learned before the programme was rolled out more widely. Phase two took place between August 2010 and April 2011, looked at how the programme was being rolled out in Hounslow, Lewisham and Lambeth and sort to address questions about the impact of the programme in changing attitudes towards organ donation and increasing the number of Black and minority ethnic people on the Organ Donor Register.

Information for phase 1 was gathered from a small sample of evaluation (n=15) forms competed by Peer Educators themselves as part of their reflective practice after they had attended events; comments made by event attendees and recorded at the end of the quiz sheet; and semi-structured qualitative interviews with the project co-ordinator and seven Peer Educators.

Information for phase 2 was gathered from an evaluation form competed by event attendees (n=800) after they had visited the stand and/or listened to a talk about organ donation delivered by the Peer Educators. Follow-up interviews were conducted with 54 event attendees who had indicated that they may sign up to the Organ Donor Register after they had had time to think.
Findings:

Phase 1:

Responses to the programme

Generally speaking, the programme was well received. When asked, members of Black and minority ethnic communities stressed how necessary it was to raise awareness of the problem in order that risks to health could be reduced:

“I believe we should support the programme to avoid lost lives.” (Event attendee)

“Need more awareness overall, maybe similar smaller sessions and more frequent.” (Event attendee)

“We really do need more information and education amongst the minority communities.” (Event attendee)

Similarly, there were positive responses to the content of the programme, with members of Black and minority ethnic communities reporting that they found the discussions stimulating and interesting:

“Very well explained!” (Event attendee)

“We had excellent discussion on organ donation.” (Event attendee)

“All members enjoyed the talk.” (Event attendee)

Raising awareness

One of the most frequently stated comments from Peer Educators was that many members of Black and minority ethnic communities simply do not know that they are firstly, at a much higher risk than the general population of requiring organ donation, and secondly, that low numbers of people from Black and minority ethnic communities donate organs. This previously reported finding (Alkhawari et al, 2005), repeatedly emerged during this project:

“I was absolutely shocked that they didn’t know what organ donation was...It’s the lack of awareness, basically, the need to educate, and need to make people aware.” (Peer Educator)

“A large number of people had no idea of how bad the problem is.” (Peer Educator)

“When you speak to them they say ‘Oh, we never gave it a thought.’” (Peer Educator)

“It was the first time that most of the people had heard about the organ donor register.” (Peer Educator)

This recognition of the need to raise awareness was also expressed by those in positions of influence in the community. The Peer Educators explained that they were welcomed into community settings and on several occasions invited back by these community leaders:
"It was the first time that they had heard about organ donation, they need more time to think about it. They have asked us to come back in six months time." (Peer Educator)

"...what they said was that they were pleased with us and they called us again when they had a health seminar in the community, and so they called us back." (Peer Educator)

As well as through direct contact with the Peer Educators, raising awareness also occurred in subtle ways. The presence of Peer Educators in community settings, the conversations they had with different individuals and the visual material such as the posters had both an immediate effect (with some people signing up to the Organ Donor Register straight away), and a gradual effect upon the intended audience:

"I think the place where we were positioned outside the main prayer Mosque, the main prayer hall, and people coming out, were stood there looking at the posters, it made them think...on the first day we had nobody signing up, I was saying you know I don’t think we are going to get anyone to sign up but before the end of the [second] day we had four people sign up.” (Peer Educator)

"At the Stanmore Library, we met a Gujarati gentlemen who when he approached said, "Oh! I have seen this before”. On probing, he said that he had met someone at the community place in Hayes - he was referring to our very first event at the Navnat Janmasthami Mela!! He had seen us, talked to us but was not yet ready to do anything about it. Whereas this time around, he spoke to us at length and finally signed up!” (Peer Educator)

"...people are listening, and people generally don’t know about it, and when you talk about it they will listen to you and even if they don’t sign on they will take the leaflet away, and promise to read it and all that stuff, you know. I think as long as people are talking it’s happening, it’s chipping away". (Peer Educator)

Importantly, the need to challenge perceptions was seen as key by the Peer Educators. This resulted in one of the Peer Educators obtaining a copy of a fatwa on organ donation. This fatwa was then used successfully to inform Muslim communities during different events:

"...what one of the health trainers has done is that she has got a copy of the fatwa that was issued by The Muslim Law (Sharia) Council on organ donation which is basically supporting it and saying that it is fine to do it whereas many community and religious leaders think that it is something that they shouldn’t do and so it is actually countering that.” (Peer Educator)

The impact of using Peer Educators

Peer Educators were primarily drawn from the local communities. The tactic of using a Peer-led approach allowed barriers to be negotiated which a non-Peer approach would have struggled to address:
“...in the past they have seen other people do work like this but they haven’t found that they were very open about explaining their perceptions of religion and background and cultural issues and barriers, and when they saw someone from their own community they felt comfortable.” (Peer Educator)

“It helped obviously in the African community because I had my badge and they could see my name on it, and it’s an African name and so they were more moving towards me, a lot of people came to me, when I did the African [event] they came more to me than to my colleagues...they thought they can trust me more because I come from the same community, I speak the same language.” (Peer Educator)

Congruent with the reports from Peer Educators themselves, the interviewees stated that having the programme delivered by individuals drawn from Black and minority ethnic groups made a significant impact on them and contributed to their decision to engage with the project:

“...it was good the way it was and I think the fact that she was also a Muslim herself also helped because when you think about organ donation you don’t think about Muslims donating organs, because I think a lot of people think that it’s not permitted, so when you see somebody that is an obvious Muslim because she’s wearing a headscarf then it kind of makes you want to investigate more so I think that was a good thing.” (Event attendee)

“It did make a difference yeah, I’m not saying I wouldn’t have spoken to a white person, but it did make a difference.” (Event attendee)

“...yes I think so because they could make the point better that there is shortage of donors amongst these groups, ethnic groups.” (Event attendee)

“I think so because I am Muslim and she was a Muslim and so she was answering questions to do with religion, which you sort of feel better about...If you are from a specific cultural background you do feel more secure asking those questions, because you think, you sort of know, they have some of the same experiences as you.” (Event attendee)

“I think it was important that the people on the stand were Black and Asian because most of the people there were Black or Asian and they were talking about things that affect Asian people so it is right.” (Event attendee)

However, this type of response wasn’t universal, with some interviewees stating that having the information delivered by members of Black and minority ethnic communities did not significantly affect them:

“To me it doesn’t matter, the information was more important than that, it was fascinating not the person who was giving it, I think because the information was interesting I would have taken it from anybody.” (Event attendee)
“It didn’t make a massive difference to me that the people on the stand were Black and Asian but thinking about it, it does seem, I don’t know, right that Black and Asian people should be involved in giving out this information. There are some people that I know who would be less likely to talk to a white person about things like this, they are mainly older people that I know.” (Event attendee)

“I’d seen an advert on television so I was aware of the issues, yeah. Not really to do with the people, I think it’s more the fact that I had prior knowledge the advert prepared the ground, so to speak.” (Event attendee)

Nevertheless, the majority of responses suggest that having the information delivered by members of Black and minority ethnic communities appeared to have a significant positive impact, encouraging members of these communities to engage, suggesting empathy with experiences and promoting a sense of security.

The success of the Peer approach seems to be underpinned by the fact that all but one of the Peer Educators were also Health Trainers, a role which involves working with members of the community, planning appropriate interventions and working on a one-to-one basis to motivate individuals to change their behaviour (Department of Health, 2009). The team manager explained:

“In dealing with health trainers part of the training was already done in effect, they just needed specific training about organ donation and the need for it and all the rest of it but other skills they already had training on so they could go out there and do it.” (Team manager)

The Peer Educators themselves proved to be very resourceful, using their initiative and networking skills well to secure more events to disseminate at, so more communities could then be easily accessed. This was a skill that they used and developed for the first time in this project as it hadn’t been a process that they’d been involved in with their other activities.

**Use of direct experience of organ donation**

In support of previous work, the use of ‘real’ people who have experience of organ donation significantly increased the impact of the programme. Sometimes this use of direct experience was intentional, sometimes this process was serendipitous:

“I had asked a family friend who has had a kidney transplant last year. A large number of people wanted to talk to her and ask her questions and she could answer them there and then.” (Peer Educator)

“[One of the people present] shared her own experience with everyone. She was only 29 when her husband was taken ill and all within 21 days of diagnosing him with kidney failure, she lost him. All those in the room knew her well and were touched by her sharing her real life experience with them. She also told them that she has signed up her whole body and this had them thinking. This active participation from the group was very effective.” (Peer Educator)
Use of community leaders

Peer Educators confirmed the findings of earlier work suggesting that it is crucial to engage with community leaders as they are understood to have great influence on beliefs and behaviour:

“...working more slowly with community leaders to get them on board, they may not always be a religious leader but they will be the person who is coordinating the group, and so work with them, get them on board, so it is almost like you have to do a presentation to them first, then you have to do it to the whole group.” (Peer Educator)

“...an Imam being there when the actual operation is being carried out, and they see how it’s done and so forth, and they talk to the community and they see how it’s done and its agreeable I think more people would sign up.” (Peer Educator)

The importance of reflection

Peer Educators were required to complete evaluation forms after event in order to encourage them to reflect on what had worked well and what had not. Peer Educators were continually assessing their own work and attempting to improve upon it. For example, during an event a problem with layout was immediately addressed:

“Due to the layout of the floor it was hard to direct everyone to the stand and so I stood at the entrance with small Kidney Research concertinas [concertina style kidney information cards] and directed people to pick more information at our stand and more than a fair share did actually visit us after.” (Peer Educator)

Reflective practice also provoked further conversation between the Peer Educators and the audience:

“...it makes them think about it, and it gets them involved and that makes us say more about it, if you see what I mean, and they ask questions and we ask questions and so a conversation takes place through that and you know they find out more.” (Peer Educator)

This type of reflection in-action is considered critical to generating more effective practice, especially amongst the human services (Schön, 1983). This emphasis on reflection may also underpin the awareness on the part of the Peer Educators that whilst the events were considered to be successful, it was still understood that there was ‘much work to be done’:

“I had good events that were positive in the sense that there was a lot exposure but there is huge, huge, huge amount of people still that were very reluctant. It is a good start but it is just a pin-drop in the ocean.” (Peer Educator)

“I still feel there is a huge area that needs to be worked with, particularly the African community. I went to an event where there was a lot of people from Sudan and I only got one person sign up even though I talked to lots of people.” (Peer Educator)
This maintenance of a reflective and critical position on practice seems essential to maintaining and building on the successes of events.

**Phase 2:**

Between August 2010 and April 2011 the Peer Educators attended more than 70 different community events. These included a number of large scale events such as the East London Mela in Barking Park, Ilford and the Tamil National Rememberance Day and the Best of Nigeria Expo events, both at Excel, Docklands, all of which were attended by tens of thousands of people, through to exhibitions in local libraries and civic centres and a number of smaller events such as attendance at a number of seniors luncheon clubs, meditation groups, womens groups and yoga sessions. In total, it is likely that the stands have been seen by more than 50,000 people.

800 questionnaires were received and analysed from attendees who visited the stands during the above period. 57% of respondents were female. 56% were aged 31-50, 22% were aged 18-30, 19% were aged 51-70 and 3% were aged 71 or over.

Participants were asked to self-define their ethnicity. As table 1 reveals, participants identified as coming from 50 different ethnic groups, with the majority defining themselves as either Asian or Indian.

![Table 1: Ethnicity of respondents](image)

Participants were asked to rate their response to the programme on a brief Likert type questionnaire immediately after they had spoken to the Peer Educators. These responses are shown below in table 2.
Table 2: Participant responses to the programme using Likert scales

Analysis of these responses is complicated because of the numbers of people who did not answer this question. It seems most likely that the reason for non-responses relates to the format of the questionnaire and the fact that participants did not realise that it went over on to a second page. If these are discarded then most respondents (n=386/515; 75%) felt that they had learned a lot about organ donation. 59% (n=287/491) said that they were more able to talk to family. 55% (n=273/500) felt that their attitudes had changed. 47% (n=230/494) said that they were more likely to join the Organ Donor Register.

Out of the 800 responses analysed, 102 (13%) signed the Organ Donor Register on the day and 75 (9%) had signed previously. 144 (18%) indicated that they needed time to think and may sign at a later date and 95 (12%) said they would sign within a month. Most of the remainder (45%; n=362) indicated that they would not consider signing the register¹.

These results show that approximately 13% of people who are engaged by the project register on the Organ Donor Register immediately with a further 12% expressing a strong inclination to do so in the next month and 18% indicating they may sign after they have had ‘time to think’.

¹ Data was missing for 22 respondents
Further analysis was undertaken of those respondents (n=362) who indicated that they would not consider signing up to the Organ Donor Register. On the questionnaire participants were asked: ‘Have you ever considered organ donation’ (Q.8) then asked ‘If no, would you consider signing up to the organ donation register?’ (Q.9).

Participants were asked to indicate their reasons for stating ‘no’ to Q.9 from a choice of seven responses:

- I don’t agree with it;
- I don’t know enough about it;
- I don’t know how to go about it;
- It scares me;
- My family don’t approve of it;
- My religious beliefs forbid it;
- Other reasons.

358 out of 362 possible respondents provided additional information as requested, with many ticking more than one of these reasons. The findings are set out in table 4.
‘I don’t know enough about it’ and ‘It scares me’ were the most common reasons for ticking ‘no’ to Q.9. However, when allowed space to expand upon their reasons (Q.11), a more nuanced picture was articulated by many participants. Despite stating that they wouldn’t register on the Organ Donor Register these respondents repeatedly stated that they thought that organ donation was a ‘good idea/good thing’:

‘I think it is a good thing but it is not for me at this present time.’ (Event attendee)

‘Cultural difficulties, I guess there’s some understanding needed in these matters. A good campaign indeed!’ (Event attendee)

‘It is good to offer an organ to save someone’s life but one has to be psychologically prepared and more knowledgeable.’ (Event attendee)

‘It’s a life saving procedure very essential. Not mentally prepared to go through with it considering my young age.’ (Event attendee)

‘I feel if a life can be saved by donating an organ to a person in need I agree. But I feel at this point in time I cannot sign up for organ donation. But this does not mean I may not change my mind at a later state in my life.’ (Event attendee)

‘Very good idea, can save lives, my brother died of kidney failure after being wounded in the Angolan conflict. I was asked to donate a kidney. Did
not do it was too afraid – still bothers me. This was more than 30 years ago.’ (Event attendee)

‘It’s a generous idea to be part of this great donation, making use of the valuable parts of human who are in need of them to lead their further life and one needs guts to do it. I appreciate all those organ donors who have saved millions of lives.’ (Event attendee)

Importantly, those who stated that they would not join the Organ Donor Register because either their religious beliefs forbade it or their family would not approve also demonstrated nuanced attitudes when responding to Q.11.

‘I think it is a great thing if you believe in it but it is hard when you believe that when it is your time, it is your time to go.’ (Event attendee)

‘Good idea, I need to research on whatever is allowed in Islam.’ (Event attendee)

‘It helps so many families, it clearly is a disease area like many others that as a community we tend to ignore and forget.’ (Event attendee)

‘Due to my religious belief, I do sympathise but also in conflict with the concept I have not decided.’ (Event attendee)

‘I disagree because it is against my religion. I may feel that in the future I may agree in being a donor.’ (Event attendee)

These responses suggest that whilst belief continues to be a factor in people’s understandings about organ donation and in making decisions about whether or not they wish to become donors personally, it is not a barrier to acceptance of the necessity for it. Beyond this, it seems that even though people stated they ‘wouldn’t consider’ signing the Organ Donor Register the actual responses are more ambiguous. With ongoing awareness raising and discussion, some may be persuaded to register. Significantly, this process of persuasion occurred during the interaction between the Peer Educator and participants. For example, a gentleman stated:

‘It’s very complicated there are always problems with transplant, natural body is always natural. The body which we are carrying is not ours in my religion, if you want to help you can but you can’t give your body parts.’ (Event attendee)

However, after speaking to the Peer Educators this gentleman was satisfied with the explanation they gave him and signed the Organ Donor Register. Similarly, one of the Peer Educators explained:

“...there was this youngish woman, who said ‘You know it was against the Muslim religion’, and we gave her the fatwa to read and she sat there in the library reading it, came back afterwards, signed the form and went away and that was quite an uplifting experience.” (Peer Educator)

Nevertheless, it was also evident that a small minority maintained views that seem particularly intransigent to donation:
‘Most people who need organ donation have done damage to themselves. Unless I know the person, I will not consider organ donation.’ (Event attendee)

This view of who is ‘deserving’ of donated organs was infrequently expressed. This particular barrier to donation is a subjective, personal position, which seems resistant to awareness raising programmes such as this one. Several of those who were engaged also stated they were superstitious about signing the Organ Donation Register. One of the Peer Educators described one person’s fears:

‘She said if she signed up her husband would be very very angry as it is as if you would be wishing death upon yourself if you signed up.’ (Peer Educator)

This type of anxiety, what was regularly described as ‘it’s just my superstition’, again seems to be a personal subjective position, which appears resistant to this particular type of awareness raising programme.

Follow up interview data

54 respondents who said that they would either sign the Organ Donor Register in the next month or may do so when they had had more time to think and who consented to being followed up were interviewed over the phone 3-4 months after the initial event.

Data from the follow up interviews suggests whilst intentions are good at the point of contact with Peer Educators, these good intentions do not appear to be strong enough to result in the person subsequently signing the Organ Donor Register. None of those who indicated that they intended to sign the Organ Donor Register either within the following month or after they had had time to think had done so:

“Not yet!”

“I haven’t yet, obviously I have not committed to anything, but it was good to know and good to have thinking time, I need the thinking time because there are the cultural things, they aren’t rational they are cultural.”

“I haven’t done it yet.”

“I haven’t spoke to the family yet but I think I will.”

“No I haven’t yet, sorry!”

Discussion and conclusion

Generally speaking, the programme was well received. There were positive responses to the content of the programme, with members of BME communities reporting that they found the discussions stimulating and interesting. The programme has been effective at raising awareness of and challenging perceptions about organ donation.

The use of Peer Educators from Black and minority ethnic communities has been important as has been the decision to recruit Peer Educators from a pool, of Health Trainers who already had experiences and skills similar to those required. The use of a quiz as an ice-breaker to help promote discussion has been an important
tool of engagement. The reflective practice model employed by the team has also been important.

A sample of 800 evaluation questionnaires completed following attendance at an event was analysed to assess the impact of the scheme. Most respondents (n=386/515; 75%) felt that they had learned a lot about organ donation. 59% (n=287/491) said that they were more able to talk to family. 55% (n=273/500) felt that their attitudes had changed. 47% (n=230/494) said that they were more likely to join the Organ Donor Register.

These results show that approximately 13% of people who are engaged by the project register on the Organ Donor Register immediately with a further 12% expressing a strong inclination to do so in the next month and 18% indicating they may sign after they have had ‘time to think’.

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The nuanced responses of those who stated that they would not join the Organ Donor Register because either their religious beliefs forbade it or their family would not approve suggest that whilst belief continues to be a factor in people’s understandings about organ donation and in making decisions about whether or not they wish to become donors personally, it is not a barrier to acceptance of the necessity for it. Even though some people stated that they ‘wouldn’t consider’ signing the Organ Donor Register the actual responses are more ambiguous. With ongoing awareness raising and discussion, some may be persuaded to register.

The findings strongly indicate that this approach is suitable for purpose. It is well received and it increases the numbers of those from Black and minority ethnic communities who register as organ donors.
References


