Promoting organ donation through Basic Life Support Training – outcomes from the #conversations study.

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Abstract

Background: More than 6000 people are waiting for an organ transplant in the UK. Although a recent change in organ donor legislation to an opt out system is hoped to address this disparity expert review highlights that 'opt out' is only one of several factors that impact organ donation rates. Studies show that ethnicity, religion and cultural influences impact opinions towards organ donation. The importance of education is well established and interpersonal educational interventions have been shown to be more effective than mass media approaches to changing behaviour around organ donation. This study evaluates the impact of an educational intervention delivered with Basic Life Support training prior to the change in legislation to positively influence views on organ donation.

Methods: An educational film promoting organ donation was developed from patient's stories, evaluated, reviewed and embedded into BLS training. All staff attending BLS training were invited to participate in the study, complete a baseline survey, watch the film and complete another survey 3-5 working days after the training.

Results: During the study period 338 attended BLS training, 8 out of 10 agreed to participate in the study, 6 out of 10 stayed behaving for the intervention and 3 out of 10 completed all stages of the study. Support for organ donation was almost universal in the baseline survey and of those who completed the study, >9 out of 10 felt the intervention had helped them understand the need for organ donation and 1 in 2 had subsequently discussed organ donation with their family and friends. 1 in 4 did not support the forthcoming change in organ donation legislation.

Conclusions: A brief targeted intervention delivered through BLS training is effective in promoting discussion and improves support for organ donation. The mandatory nature of BLS training reduces bias in engagement and offers huge potential for delivery of a limited intervention around organ donation at pace and scale. Further understanding of NHS staff awareness of and opinions to the change in organ donation legislation is warranted.

Trial Registration

#conversations was prospectively registered with the ISRCTN on 23/01/2019.

ISRCTN 36338010

IRAS project ID 233611

Background

In the UK, 6077 patients were waiting for a life-saving organ transplant at the end of March 2019⁽¹⁾. On average 3 people die each day in need of an organ and only 1% of people die in circumstances where donating an organ can be considered⁽²⁾. When asked, 90% of the UK population were supportive of organ donation in principle⁽³⁾, but many people did not make this decision clear either by signing the NHS Organ donor register or discussing their views with families and friends, as evidenced by only 38% of the population having signed up to the organ donor register by March 2019⁽⁴⁾.

In response to this the Government introduced a change in legislation. From spring 2020 organ donation in England, Scotland and Northern Ireland is moving to an opt-out system, where all adults are considered to have agreed to be an organ donor when they die unless they have recorded a decision not to donate or are in one of the excluded groups⁽⁵⁾. Wales introduced this legislation in December 2015, encouragingly this led to significant improvements in support for organ donation with the highest organ donation rate per million population in the UK in 2018/19⁽⁶⁾. However moving to an opt-out system for organ donation does not automatically lead to an improvement in organ donation rates; a study comparing data from 35 countries registered with the Organisation for Economic Co-operation and Development (17 countries classified as opt-out, 18 classified as opt in) demonstrated no significant difference in deceased donation or solid organ transplantation activity between opt-out and opt-in countries⁽⁷⁾ and expert review highlights 'opt out' as only one of several factors that impact organ donation rates⁽⁸⁾. This suggests that there are other barriers to organ donation that must be addressed. Additionally concerns regarding the change in legislation have been raised by the public^(9, 10) and the importance of education is well described⁽¹¹⁾. There is little published evidence on the opinions of NHS staff to the change in organ donation

legislation, but evidence from Greece showed Health Care Professionals had both a lack of knowledge about organ donation and the change in legislation to a soft 'opt out' from 2013^(12, 13), highlighting the importance of education and training.

UK studies have shown that ethnicity, religion, cultural and familial influences can be a barrier to organ donation^(14–17). Consent rates in the UK in 2018/19 of 43% for Black, Asian and minority ethnic families and 71% for families from a White background⁽¹⁸⁾. Beliefs often need to be understood through a broader narrative and multiple influences interact on each individual's approach to organ donation⁽¹⁹⁾. Having open and honest conversations with family and friends is therefore very important. The recent change in legislation presents an unprecedented opportunity to raise understanding of the importance and impact of organ donation and to positively influence opinions towards organ donation. A systematic review by Deetat *et al*/showed Educational interventions with strong interpersonal component were more effective than mass media approaches to successful change behaviour around organ donation⁽²⁰⁾.

The NHS in England is the country's biggest employer with 1.5 million employees⁽²¹⁾ and has higher ethnic diversity than the UK population. In 2018 data showed the UK population was 87.2% White and 12.8% non White⁽²²⁾, whereas NHS staff were 80.2% White and 19.8% non-White⁽²¹⁾.

All NHS staff with direct patient contact are mandated to have Level 2 Adult Basic Life Support (BLS) training provided by the Resuscitation Council UK⁽²³⁾. BLS training is typically delivered in small groups by experienced BLS trainers as a combination of taught and practical experience. Emotion has a substantial influence on the cognitive processes including perception, attention, learning, memory and reasoning⁽²⁴⁾. A study in teenagers showed that attending BLS training had a significant improvement in positive emotional scores⁽²⁵⁾. While there is no comparable evidence for adult NHS staff attending BLS training, there may be a similar opportunity to create a positive environment to learn about organ donation.

The purpose of this study was therefore to develop and evaluate a simple educational tool using a narrative approach to promote conversations, understanding and support of organ donation delivered through BLS training.

Methods

A survey based on questions derived from the NHSBT Optimisa Survey 'Understanding current attitudes and behaviours towards organ donation in England'⁽³⁾ was used in 2016 to gather data on local attitudes and behaviour in working age participants in Teesside (North East England)[Appendix 1]. Findings highlighted the need for additional educational tools to support decision making around organ donation and registration on the organ donor register. Several respondents to the survey identified that they would be willing to be part of a focus group to discuss and evaluate educational tools to promote conversations on organ donation. This focus group was convened in 2017 and work from this group led to the #conversations study. #conversations is a short film exploring the impact of organ donation on the wider family. It was developed in partnership with families who had direct experience of organ donation (both donating and receiving) in 2018. Individual interviews were based on questions around the impact of organ donation on their everyday lives and the visual styling placed emphasis on telling stories, aiming to create a design that was visually interesting and full of meaning while based on ordinary and every day activities^(26–28). This would demonstrate to viewers that conversations around organ donation ought to be conceptualised as a normal part of everyday social interactions and reduce fear and hesitancy around the subject, as evidenced in published studies^(29, 30).

A bespoke sound track was developed by Principle Sounds© and added to the film. The approach to the underscore music for the video was to support the message through emotional engagement⁽³¹⁾. The film was then reviewed by the families, the focus group and BLS trainers for feedback on the content and style of the film. The film was embedded into BLS training and evaluated as a NIHR portfolio research study IRAS:233611.

Participants attending BLS training at 2 Hospitals in the North East of England (The James Cook University Hospital in Middlesbrough and the Friarage Hospital in Northallerton) during the study period were invited to participate. All those attending BLS training were informed about the study by details on the introductory slide set and by participant information leaflets and consent forms on their seats. Attendees were asked to complete a baseline survey about their opinions of organ donation prior to the start of the BLS training [Appendix 2]. Attendees were invited to watch the film at the end of BLS training and consent was gained for those willing to stay in the study and complete the follow up questionnaire [Appendix 3]. All those who consented to remain in the study received an email

link to the second questionnaire 3–5 working days after they attended BLS training. The study was run on 12 days between 14th January-28th February 2019.

Qualitative data were collected from participants via semi-structured interviews using a topic guide [Appendix 4]. The follow up questionnaire contained an open invite to all recipients to take part in an interview; interviewees were randomly selected from those who agreed to participate and gave written informed consent. Interviews were audio recorded, transcribed verbatim and anonymised. Interviews explored the response to the film, feelings about organ donation and the reasoning behind the choices made. The interview data were reviewed using a thematic analytic framework, with emergent themes discussed with the research team and a consensus reached on the final set of themes⁽³²⁾.

The film can be viewed here

<https://vimeo.com/294336992>

Password: #conversations2019

Results

Staff Survey 2016

A summary of responses is shown in Table 1. Support for the principle of organ donation was higher in the NHS staff group than the general population (96.3% vs 85%⁽³⁾) as was registration on the organ donor register with 3 in 4 stating they were on the organ donor register compared to 1 in 3 of the general population⁽⁴⁾. However despite this only 2 out of 3 staff said they knew how to put their name on the register and 2 out of 3 said they had enough information about organ donation for them to be able to make a decision. Both the subsequent change in legislation and this lack of confidence about having enough information to make a decision highlighted the need for additional educational resources to support decision making and the development of #conversations study.

Table 1
Summary of responses to the 2016 staff survey

Question	% Response
Do you support the principle of organ donation?	Yes 96% No 4%
% Responders who thought they were already on the organ donor register*	Yes definitely 58% Yes I think so 18% (Total 76%)
Proportion of staff who confirmed they knew how to put their name on the organ donor register	64%
Proportion of staff who confirmed they had enough information to make a decision about the organ donor register	67%
*Organ Donor registration by TS postcode 37% April 2016 (personal communication NHSBT)	
NHS Respondents from South Tees Hospitals NHS Foundation Trust (n = 335)	

#conversations study

During the study period 338 staff attended BLS training and were eligible to take part in the study. Participation in the trial was high as illustrated in Fig. 1, with 81.9% taking part in the initial questionnaire, 60.7% consenting to stay and watch the film and 27.5% completing the follow up questionnaire.

Figure 1: Flow chart of participation in the #conversations study

Demographic data

Table 2 shows the difference in sex, ethnicity and median age range across the 2016 staff survey, #conversations baseline and follow up questionnaire. The staff profile most representative of the Trust was the #conversations baseline study questionnaire responders. Acknowledging that the views of those who did not take part in the study are not represented, (18.1% of those attending BLS training), the baseline survey shows support for organ donation remains high amongst NHS staff (99% supportive).

Table 2
Responder demographics for staff survey and #Conversations study questionnaires

	Staff Survey 2016*	#Conversations Baseline study Questionnaire	#Conversations Follow up study questionnaire
Number of responders	335	277	93
Sex	90% Female 10% Male	83% Female 17% Male	85% Female 15% Male
Ethnicity	95% White British or other White 1% Asian 1% Black 3% Mixed/other	84% White British or other White 9% Asian 0% Black 7% Mixed/other	96% White British or other White 3% Asian 0% Black 1% Mixed/other
Median age range	45–54 years	24–34 years	35–44 years
% of responders who support the principle of organ donation	94%	99%	n/a
* For the purpose of this study only responses from South Tees Hospitals NHS Foundation staff were used so that the data could be compared.			

Summary of responses from follow up questionnaire

As shown in Fig. 1–1 in 4 completed the follow up questionnaire. Participants agreed that the film had helped them understand the need for organ donation (94.6%) and the impacts on the family (93.6%). Since watching the film 4 out of 5 had thought about organ donation, 4 out of 10 had talked to their colleagues and 1 in 2 had talked to their family about organ donation. More than 40% of responders were more supporting of organ donation having watched the film (Table 3).

Interestingly despite this widespread support for organ donation 1 in 4 were not comfortable with the proposed change in legislation with 16% unsure and 8.6% unsupportive.

Table 3
Summary of responses to the follow up questionnaire

Question	Response
After watching the film #conversations about organ donation did the film help you understand the need for organ donation?	Yes 95% No 5%
After watching the film #conversations about organ donation did the film help you understand the effects on the family?	Yes 94% No 6%
Since watching the film have you thought about organ donation?	Yes 85% No 15%
Since watching the film have you talked to your work colleagues about the film?	Yes 43% No 57%
Since watching the film have you talked to your family about your views on organ donation?	Yes 51% No 49%
Since watching the film are your views on organ donation?	More supportive 42% Just the same 58% Less Supportive 0%
Having watched the film do you support a change to the opt out policy for organ donation which means that everyone is presumed to be happy to donate their organs unless they opt out of doing so?	Yes 75% No 9% Not sure 16%

Qualitative data

A description of the 6 participants interviewed and the impact of the film on their discussions and opinions is shown in Table 4. There was a range of opinions expressed about the change in legislation to 'opt out' from strongly supportive to strongly negative and support for the change in legislation did not correlate with support for organ donation in principle. From the participants interview data three main themes were identified; impact, autonomy and education.

Table 4
Description of the participant interviewees and responses to the film

	Participant					
	1	2	3	4	5	6
Age group	45–54	25–34	45–54	35–44	45–54	45–54
Sex	Female	Male	Female	Female	Male	Male
Supportive of organ donation in principle	Yes	Yes	Yes	Yes	Yes	Yes
Supportive of change in legislation to 'opt out'	No	Yes	uncertain	Yes	Yes	uncertain
Spoke to family about organ donation after participating in the study	Yes	Yes	Yes	Yes	Yes	Yes
Spoke to work colleagues about organ donation after participating in the study	Yes	Yes	Yes	Yes	No	Yes

Impact

All participants agreed the film was impactful

'I think having people who've been through it on the film, it was really emotive' 'I was thinking it's really important that we have this conversation' Participant 1

'It's real people, It's not voiced by actors... so you think, Oh, that could be so and so, from down the road' Participant 5

'I keep coming back to the grandparents, doing the homework with the kids, I mean it's that simple thing, you know' Participant 6

[The film] gets a message across without it... scaremongering or making people recoilyou just encourage them...you nudge people, I guess, rather than telling them, "You must do this," because people don't react very well to that' Participant 5

Although one participant did not feel that the film went deep enough *'It just sort of skirted over the top'* Participant 3.

No participants raised concerns about the film making them feel uncomfortable.

Autonomy

All interviewees thought it was important to listen to and respect the views of an individual when it comes to organ donation.

'Like everything else we do in healthcare, it's important that we get their views and we respect, honour and fulfil their views' Participant 1

'People should be able to make their own decisions' Participant 4

This was particularly pertinent when discussing the change in legislation to 'opt-out'

'Personally I don't agree with it, ... I would find it devastating if I felt that wasn't what they wanted but they hadn't got round to opting out' Participant 1

'I'm pro the decision..... but I can see how people would view it in a negative light, potentially removing people's right to make a decision' Participant 2

Education

All participants mentioned the importance of education around organ donation, the majority felt additional education resources about 'opt-out' should be more widely available and details on the process made clearer to support people in their decision making.

'Education.. to clarify what it entails...more people would be definite' 'we work in a hospital and we don't know' Participant 3

'Education- I think that is the most important thing...opportunities to open up forums for discussion' Participant 6

All acknowledged the difficulty of having these conversations and that some people do not want to discuss or think about organ donation

Discussion

The aim of this study was to qualify support for organ donation amongst NHS staff, to positively promote awareness of the impact of organ donation on everyday lives and to stimulate conversations about individual wishes regarding organ donation with family and friends. The study achieved all these aims. Encouragingly there was almost universal support for the principle of organ donation amongst NHS staff responders in both the 2016 staff survey and baseline #conversations survey in 2019. This study was limited to frontline staff in the North East of England, as a result the ethnic diversity seen in our respondents was not representative of the wider NHS workforce and it would be interesting to see if this level of support for organ donation is seen across the wider NHS workforce. The opinions of staff who did not participate in the study and the non-responders to the second questionnaire are unknown; it is possible that these staff declined to be involved as they were less supportive of organ donation.

However despite these unknowns, even if the impact was only limited to those who completed the study (1 in 4 attending BLS), it would still have a powerful ripple effect on conversations about organ donation within the community. Participants confirmed that it had helped them understand the need for organ donation, the impacts on the family and the majority had talked to their colleagues and family about organ donation after attending the training. The use of regional accents and local patient and public engagement in developing the study strengthened the interpersonal component and minimised negative reactions to the intervention. These factors can be incorporated to offer a bespoke educational model for tackling regional variations in support for organ donation.

The NHS is the largest employer in the UK with a diverse workforce, encompassing multiple faith groups, ethnicity and cultures. BLS training is mandatory for front line NHS staff and is also delivered within the community offering unique access for engagement. Promoting conversations with family and friends about organ donation through education in this manner therefore has the potential to reach a substantial proportion of the population.

BLS Training is a cornerstone of good resuscitation outcomes in the UK and as such it is essential that any intervention affecting the training does not detract from the delivery of the training itself. Any upscaling of this type of intervention would need to be done in partnership with the UK Resuscitation Council and used wisely. Close involvement of donor and recipient families, Basic Life Support trainers and NHS staff in the development and then review of the film enabled an end product of just 2 minutes that was impactful and thought provoking without causing discomfort. For a clinical trial the study had very high levels of participation with 80% of eligible participants contributing in the baseline survey. It is difficult to estimate the effect of embedding this learning as part of BLS training, it may be that this setting creates an environment where people are more comfortable to think about organ donation and the engagement and impact would be less if delivered as part of a different mandatory training e.g. Fire Safety. BLS training could be used to promote discussion around other issues pertinent to life support. For example to educate and promote the importance of bystander CPR in witnessed out of hospital cardiac arrest.

As identified through the qualitative analysis, focusing on patient stories enriched the interpersonal component of the film and added impact. As the study was developed with local patients with regional accents, the impact of this film may be less if delivered in a different locality or region. Interviews highlighted the need and desire for more education around organ donation, particularly around the change in legislation. Autonomy was a consistent theme for the concerns raised around the change in legislation. This was despite the consistent high levels of support for organ donation in NHS staff and warrant further understanding and evaluation.

Conclusions

1. NHS staff participants in this study were highly supportive of the principle of organ donation.
2. Through this study we have developed a novel research model for delivering and evaluating short educational interventions with BLS training and a powerful tool to promote positive conversations about organ donation.
3. Interestingly 1 in 4 responders during the study period (Jan-Mar 2019) were not comfortable with the proposed changes in organ donation legislation. Therefore this study also identified the need to understand the views of the NHS workforce on the subsequent change in organ donation legislation in spring 2020 and to develop and evaluate educational tools to support staff with this change legislation across different NHS staff groups, geography and more diverse ethnicity.

Abbreviations

BLS, Basic Life Support

NHS, National Health Service

UK, United Kingdom

Declarations

Ethics approval

All methods were carried out in accordance with UK relevant guidelines and regulations. The #options study protocol was approved through the UK Integrated Research Application System, IRAS 233611.

Trial registration.

#conversations was prospectively registered with the ISRCTN on 23/01/2019. ISRCTN36338010

Consent to participate

Informed consent was obtained from all subjects.

Consent for publication

All authors and given consent for publication

Competing interests

There are no conflicts of interest

Availability of data and materials

All data is available in the appendices to the manuscript

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Contribution

Caroline Wroe, contributed to the concept and design of the study, the acquisition of data, the analysis and interpretation of the data and drafted the article.

Natasha Newell, contributed to the concept and design of the study, the acquisition of data, the analysis and interpretation of the data and to the final approval.

Marcus Diamond, contributed to the concept and design of the study, created and edited the film and contributed to the final approval.

Michael O'Malley, contributed to the concept and design of the study, created and edited the film and contributed to the final approval.

David Reaich, contributed to the concept and design of the study, the analysis and interpretation of the data and to the final approval.

Sarah Slater contributed to the concept and design of the study, the acquisition of data and to the final approval.

Yitka Graham contributed to the concept and design of the study, the analysis and interpretation of the data and to the final approval.

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Appendices

Appendix 1-2016 survey

Appendix 2-Baseline #options survey

Appendix 3-Follow up #options survey

Appendix 4-Topic guide for qualitative interviews

Figures

Figure 1

Flow chart of participation in the #conversations study

Figure 1

Flow chart of participation in the #conversations study

Supplementary Files

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