

Delivering a revolution in public behaviour in relation to organ donation: a summary of the evidence

March, 2014

Introduction

This document has been prepared for NHS Blood and Transplant, the Special Health Authority with responsibilities across the United Kingdom in relation to organ donation and transplantation.

It will also be of use to NHSBT's partners and stakeholders (within the NHS, across Government and within local communities) and any agencies that will be involved in its delivery.

This document is intended to be viewed in the context of two companion documents:

- A strategy for delivering a revolution in public behaviour in relation to organ donation
- Delivering a revolution in public behaviour in relation to organ donation: year one delivery plan

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1. International case studies

The table below contains summaries of public engagement campaigns that have been undertaken in recent years. In many instances, no evaluation is publicly available. Where evaluation is available, we have quoted the evaluation directly, and it is worth noting that in some circumstances these evaluations will refer to increasing numbers of “donors” when it is likely that “registrants” are actually what is being referred to. No validation of the external evaluations has been conducted.

Organisation	Campaign Name	Campaign Outline	References
Australia			
DonateLife	“Have the chat that saves lives” – 2014 theme DonateLife Week (ongoing)	<p>General public are being invited to get involved by promoting donation in a number of ways:</p> <ul style="list-style-type: none"> - Hosting a 'Have the Chat' dinner with family and friends - Organising a sporting event – this could be a run, walk, marathon or a sporting match - Dedicating the name of a local sporting match to DonateLife Week - Hosting an entertainment event – such as a concert or dance - Coordinating a street performance or flash mob <p>Employer campaign is asking companies to promote organ donation by:</p> <ul style="list-style-type: none"> - Placing posters on notice board, staff rooms, staff changing rooms, kitchens - Including information about involvement in DonateLife Week 2014 activities in newsletters, on the extranet/intranet and on noticeboards - Encouraging colleagues to use the screensaver or email signature images - Organising a morning tea or a BBQ lunch to raise awareness and encourage discussion - Promoting DonateLife on payslips 	http://www.donatelife.gov.au/get-involved/donatelife-week-2014
DonateLife	“Donate Life...the greatest gift” (2013 – present day)	<p>A community education campaign for people from culturally and linguistically diverse communities aimed at increasing family discussion about organ and tissue donation wishes.</p> <p>Religious and cultural leaders were invited to sign DonateLife Statements of Support to demonstrate their commitment to growing organ and tissue donation in their communities, and the start of their partnership with DonateLife.</p> <p>Additionally, through the Organ and Tissue Authority’s Community Awareness Grants Program, community projects received funding to run education activities with culturally and linguistically diverse group.</p> <p>As part of these grants projects, a range of culturally appropriate resources were developed.</p>	http://www.donatelife.gov.au/multicultural-resources
DonateLife	“OK” & “Ask and know your loved one’s wishes” (2011/2012)	<p>This was a campaign that included two TV adverts with two key messages.</p> <p>The first advert was titled “DonateLife, discuss it today, OK?” and called on the population to discover, decide and discuss their wishes.</p> <p>The second was titled ‘Ask and know your loved ones’ wishes’ and called on people to find out about their loved ones’ wishes.</p> <p>Engagement activity was targeted at the general population, with specific focus on BAME and youth community groups.</p> <p>An extensive quantitative evaluation was conducted. It was found that 52% of respondents recognised at least one element of the campaign. The main findings were:</p> <p>The evaluation found that recall of the campaign was significantly higher following the introduction of the 'Know their wishes' strand.</p> <p>The evaluation concluded that the “Know their wishes” strand should be continued more extensively.</p>	http://www.youtube.com/watch?v=KRweTygtGko

Belgium			
ReBorn Organ Donation Foundation	“Second life/Reborn” (2013)	<p>In 2013, a campaign leveraged apps that became dormant following events (e.g. music festivals). The initial idea came from the concept that many apps lose their original purpose, however, people tend to keep apps on their phones long after the app has served its original purpose. The campaign gave the dormant apps "a second life", acting as a channel to ask people to give their organs a second life too. Three of the biggest Belgian events participated.</p> <p>By the end of 2013, the Reborn apps reached a total of around 150,000 people, with a conversion rate of 11% (average is 0.3%), meaning registrations increased by 210%. Belgium calculates that one donor can save up to eight lives; therefore the new registrants could save up to 3,752 lives.</p> <p>In 2014, it is expected that more apps will be Reborn.</p>	http://uk.adforum.com/creative-work/ad/player/34485273 http://translate.googleusercontent.com/translate_c?depth=1&hl=en&prev=/search%3Fq%3Dreborn%2Bto%2Bbe%2Balive%26biw%3D1366%26bih%3D643&rurl=translate.google.co.uk&sl=nl&u=http://www.rebornapps.be/&usg=ALkJrhBM1oaquJgML1bnRX9Q6XSrtcbJQ
ReBorn Organ Donation Foundation	“Save a life while you wait” (2012)	<p>In Belgium, citizens are required to register their organ donation preferences with the town hall. However, this is not done routinely and a large proportion of the population fail to register their wishes.</p> <p>Therefore, it was decided target the audience when they were already in the town hall on other business. For example, waiting tickets had a message saying that holders could sign up now to be an organ donor.</p>	http://www.reborntobealive.be/index.php/alles-over-re-born-to-be-alive/promotie-orgaandonatie?id=91
ReBorn Organ Donation Foundation	“Hold the line and save up to 8 lives” (2012)	For World Health Day in 2012, companies were asked to replace their hold music and messages with a message about waiting for an organ transplant and signing up to the organ donation register.	http://www.reborntobealive.be/index.php/component/content/article?id=92 http://www.coloribus.com/adsarchive/directmarketing/organ-donation-hold-the-line-18464305/
ReBorn Organ Donation Foundation	“Get inside her” and “Something Good” (2010)	<p>The organ donation advertising campaigns that ReBorn ran in 2010 made bold use of humour: One campaign used images of dictators with their organs highlighted and the tagline “There’s something good in everyone.” Another campaign featured a female model in a bikini with the copy "Becoming a donor is probably your only chance to get inside her.”</p>	http://www.coloribus.com/adsarchive/prints/organ-donor-foundation-kim-jong-il-16330255/ http://www.coloribus.com/focus/agitating-organ-donation-ads/12604705/
ReBorn Organ Donation Foundation	“Obituary” (2008)	This advertising campaign creative was designed to look like an obituary page, but there was only one entry and the other entries appeared to be missing: the implication being that the one death that was logged had resulted in transplants that had saved other people. The copy read "one organ donor can save 8 lives".	http://www.coloribus.com/focus/agitating-organ-donation-ads/12257905/
ReBorn Organ Donation Foundation	“If you wish to become a donor, sign up before it is too late” (2008)	This is an advertising campaign depicting people in accidents trying to sign organ donation forms.	http://co248141.cdn.cloudfiles.rackspacecloud.com/DUVG_00743_34452337A.JPG http://co248141.cdn.cloudfiles.rackspacecloud.com/DUVG_00743_34452336A.JPG
Brazil			
Novartis	“Organ Donation Day Donate your posts”	<p>This was a social media experiment. Bloggers were invited to an information event on organ donation to raise their awareness and understanding of the issue. Bloggers were invited to record videos about their own donation wishes. On organ donation day, a random selection of the bloggers that attended the event were provided with a code to put into their blog. This would upload and take over a section of the blog with content from another blogger about organ donation. The concept being that the content had been donated. All the content and imagery for the campaign featured outstretched hands to convey the idea of donation/helping people out. 714 people contributed reaching 2 million readers in one day.</p>	
Soccer Club Recife	“The immortal fans”	<p>This integrated campaign focused on generating organ donation registrations from fans of a Brazilian soccer club. The club, Soccer Club Recife, is said to have 'some of the most dedicated fans in the world'.</p> <p>An advert was shown at the club stadium on match days. Patients that were waiting for organs spoke to fans directly saying, "I promise that your eyes will keep on watching Sport Club Recife" or "I promise that your lungs will keep on breathing for Sport Club Recife."</p>	http://www.brandchannel.com/home/post/2013/06/18/Recife-Ogilvy-Cannes-Lions-061813.aspx

		<p>Fans signed up for a Sport Club Recife organ donor card at the stadium, through a Facebook app or online (they subsequently received the card at home by mail).</p> <p>51,000 people registered for a card</p> <p>Organ donations went up 54 per cent in the country during the year the campaign ran and the campaign is thought to have played a huge part in that.</p> <p>The “Immortal Fans” campaign, took top honours in the Promo & Activations category at Cannes Lions.</p>	
Brotherhood of Santa Casa de Sao Paulo	“The Waiting Ticket” (2012)	<p>The Brotherhood of Santa Casa de Sao Paulo is a private philanthropic institution and medical facility. Encouraging organ donation is one of its areas of activity. For “The Waiting Ticket” the organisation partnered with a supermarket. The supermarket agreed to replace the Deli queue tickets with tickets with extraordinary high numbers. These numbers were equivalent to the number the person could be if they were on the organ transplant waiting list. The ticket also informed customers that they could join the organ donor register.</p>	http://www.coloribus.com/adarchive/tv-commercials/santa-casa-de-misericordia-de-sao-paulo-the-waiting-ticket-15037605/
Canada			
British Columbia Transplant	“Live Life. Pass It On” (2009 onwards)	<p>In 2009, Eva Markvoort appeared in a documentary depicting her battle with cystic fibrosis. This was followed by an art project where she was pictured unclothed, with accurate drawings of organs (such as heart and lungs) on her chest.</p> <p>BC Transplant extended this concept. Using local transplant recipients, they recreated Eva's pictures to make campaign materials. The integrated campaign 'Live life. Pass it on', ran throughout British Colombia, urging people to join the register. BC produced t-shirts with the heart and lung designs, which people could buy to demonstrate their support. They also launched the #4eva mobile app, which encouraged people to become organ donors and to spread the campaign to their contacts via social networks.</p>	http://transplant.bc.ca/Live_life_pass_it_on.htm
Trillium Gift of Life Network's (TGLN)	“Recycle Me” (2009)	<p>Research showed that young people in Ontario knew very little about the need for donors. The goal of the TGLN RecycleMe.org campaign was to educate and engage this audience, so that they could make an informed decision about becoming a donor and become ambassadors for the cause.</p> <p>The campaign launched in April 2009 and ran for thirteen weeks. It utilised transit shelter ads, interior bus ads, social media, public relations and online banner ads, which all drove people to an immersive and interactive website that balanced education with entertainment. The site itself showed a guy whose body you could zip open as he explained which bits of him were “recyclable”.</p> <p>Coverage by both national and provincial news media resulted in over sixty unique stories about the campaign and a total reach of over nineteen million.</p> <p>Downloads of donor registration forms increased by over 400 per cent versus the same period in the previous year — moving from a total of 2,180 to 11,244.</p>	http://www.recycleme.org/
Europe			
EU member states	“European day for organ donation” (Ongoing)	<p>This is an annual awareness event, promoted via an integrated campaign. The event has been running for 15 years. Each year, a different EU member-state can run the campaign; however Belgium has the highest level of involvement.</p> <p>According to the Council of Europe, the idea behind this day is to "help a different member state each year to encourage debate and provide information on organ donation and transplantation". The day is promoted via an integrated campaign.</p> <p>EDD organisers claim that of the people that see EDD communications, more than 80% say it affects their thoughts and feelings on organ donation, and those declaring they have gone on to talk about donation wishes with family is nearer the 50% mark.</p>	https://www.edqm.eu/en/European-day-for-organ-donation-1223.html http://ec.europa.eu/eahc/documents/health/conference_27-28_06_2013/EDD_-_Toolkit_for_European_Donation_Days.pdf
Trans-Forme	The Course of the Heart Race (Ongoing)	<p>This is an annual running endurance event. Leaving from Paris, and arriving in Les Arcs. The Course of the Heart Race takes 4 days and 4 nights, with runners passing the baton for organ donation.</p>	http://www.youtube.com/watch?v=OlxvcqtW8lw&feature=youtu.be http://www.trans-forme.org/sitev2/index.php?option=com_content&task=blogcategory&id=89&Itemid=230

L'agence De La Biomedecine	“D'organes, il suffit de le dire. Maintenant.” (Organ donation, just say so. Now) (Ongoing)	<p>The National Day of Commemoration of Donation and Organ Transplantation, June 22, is an annual event that has been running for over ten years.</p> <p>In 2012, it was revised to become the National Day of Reflection on Organ Donation and Transplantation and Donor Recognition.</p> <p>In 2013, a TV advert ran which depicted French personalities being seen calling their families and talking about organ donation. The theme of the ad was “Organ Donation, just say so. Now.”</p> <p>The campaign was directed by Eric Toledano and Olivier Nakache, the filmmakers behind the successful French film <i>Untouchables</i>.</p>	http://www.youtube.com/watch?v=H4Jh1X4eJzo
Fédération des Associations pour le Don d'Organes et de Tissus Humains	Advertising campaign (2008)	In 2008, ADOT ran two advertising campaigns. One was called “You can be a hero after you die” and depicted people in accidents. The other featured pictures of organ donor recipients, hugging the ghosts of organ donors and the copy read: “Thousands of people owe their life to organ donation”.	http://www.coloribus.com/focus/agitating-organ-donation-ads/11972905/ http://www.ufunk.net/en/publicite/france-adot-une-campagne-poignante-pour-le-don-dorgane/
Germany			
Bundesministerium für Gesundheit	“Ralf Schmitz On Stage” (comedian) (2013)	This was a video campaign based around humour. The advert was a series of clips of German comedian Ralf Schmitz, standing on stage, making jokes about organ donation. He then advises viewers to hang onto their organ donor card.	http://www.bmg.bund.de/ministerium/presse/pressemitteilung/en/2013-03/neuer-spot-zur-organspende.html
Furs Leben	“Heaven security point/Man at bus stop” (2013)	This campaign involved multiple television adverts based around the concept of waiting. In one advert, there is a queue of people at an airport-style security checkpoint at the entrance to Heaven. As a man struggles with heavy bags, a woman with no luggage enters the scanner. When she is scanned, her heart is missing. She is asked what has happened to it, and she says she has donated it. Another advert showed clips of a man waiting at a bus stop. As he waits, two buses drive past, and his surroundings change from day to night. A third bus then appears and stops, but as the driver opens the doors, the man waiting drops dead. A caption says that 12,000 people in Germany are waiting for an organ transplant, but many are waiting for too long.	http://www.fuers-leben.de/informieren/downloads/im-himmel-braucht-man-kein-gepaeck.html
Furs Leben	“Extreme waiting at the platform” (2012)	This advert shows a clip of a man on a life support machine, waiting on a train platform. People walk past him and are alarmed by his condition. Behind him there is a caption, 'some of us are waiting longer for an organ donor. Help with an organ donor card'. There were also posters for this campaign which showed other people who are waiting for transplants.	http://www.youtube.com/watch?v=3GVWUoplBek
India			
The Times of India	“Organ Donation Day” (2013)	<p>The Times of India ran a special campaign supporting organ donation.</p> <p>Over 50,000 people pledged their organs as a result of the day. This is substantial, especially when compared with 2012, when there were fewer than 40,000 registrations in the whole year.</p>	http://timesofindia.indiatimes.com/TOI-campaign-on-organ-donation-garners-50000-plus-pledges/articleshow/21665261.cms
Vision Foundation of India	“Don't kill your eyes” (2008)	This campaign consisted of three print adverts, which featured a pair of large eyes in suicidal scenarios – on a train track, hanging from a tree by a noose and about to jump from a high ledge. The copy read “don't kill your eyes...donate them instead”.	http://osocio.org/message/dont_kill_your_eyes

Netherlands			
BNN – Dutch TV Channel	“The Big Donor Show” (Television series) (2007)	<p>This campaign centred on a fake reality television game show. An actress played a terminally ill woman, Lisa, who was tasked with deciding which of twenty-five people requiring transplantation to donate her kidney to. The candidates were real patients, who agreed to participate in the show to give awareness to the limited number of organ donors in the Netherlands. The series created a lot of controversy, until the final episode where it was revealed that the show was a hoax, and Lisa was an actress.</p> <p>Viewers were encouraged to send advice on who they thought she should choose to give her kidney to via text messages. The profit made by the text messages was given to the Dutch Kidney Foundation.</p> <p>As a result of the programme, 50,000 people requested an organ donation form to be sent to them. It also won an international Emmy for "non-scripted entertainment".</p>	http://en.wikipedia.org/wiki/De_Grote_Donorshow
Spain			
La Organización Nacional de Trasplantes (O.N.T)	“Eres perfecto para otros” ("You're perfect for others") (2012-2013)	<p>The campaign was described as a "12 month twofold promotion" and took place in 2012-13.</p> <p>The first focus was to encourage potential donors to decide to sign up to the register; the second was to make those who have signed the register see the importance of communicating their decision to friends and family.</p> <p>The campaign used broadcast and online channels and an app called “I’m giving”</p> <p>More than 185,000 people applied for organ donor cards between early 2012 to June, 2013. It is presumed that this is largely due to the campaign.</p>	www.eresperfectoparaotros.com http://www.saludymarketing.es/blog/2013/01/la-campana-eres-perfecto-para-otros-supero-con-creces-las-expectativas/
Switzerland			
The Federal Office of Public Health in Switzerland	“The Decision on a Cliff-hanger” (2013)	This was a 2013 television advert consisting of a four-minute discussion between two men about organ donation. The men are in a car suspended over the edge of a cliff discussing the issues surrounding the decision to donate, and actually signing up to get a card. The advert ends with the tagline 'decide for or against donating your organs...but don't wait too long, otherwise your relatives will have to decide'.	http://www.transplantinfo.ch/
Thailand			
Thai Red Cross Foundation	“The Beauty of Giving” (2010)	<p>In this 2010 campaign, True Corporation helped the Thai Red Cross foundation shift perceptions towards organ donation. The low number of such donations in Thailand stems from an old, deeply-held, cultural belief that being buried or cremated in a state that is not "whole" would result in a handicapped reincarnation.</p> <p>The campaign's "The Beauty of Giving" idea suggested organ donation would become the most beautiful "Merit" one could enact in a lifetime. Celebrity artists from different fields were invited to create pieces inspired by human organs to be showcased in "The Beauty of Giving Art Gallery". All the works were used in various forms of advertisements and in an online gallery, where visitors were also allowed to create and share their own virtual artworks. The gallery also went on tour around Thailand.</p> <p>Within three months of launch, 9,624 people became “donors”.</p>	

USA			
Donate Life	“License Plates” (Ongoing)	In select states, people can apply for a Donate Life license plate that has the messages to encourage others to register as an organ donor. There is a fee of approximately \$50 for the plate. The money does not go to Donate Life and it does not seem to be a requirement to be on the register to buy the plate.	
US Department for Health and Human Services	“Workplace Partnership for Life” (2001 – present day)	<p>This is a national initiative, created in 2001, that unites the U.S. Department of Health and Human Services (HHS) with the organ and tissue donation community and businesses, organisations, and associations to spread the word about the importance of organ, eye, tissue, blood, and bone marrow donation and to encourage the American public to register as donors. This nationwide network of more than 11,000 “Partners” includes local, regional, and national companies, associations, unions, and academic, volunteer, philanthropic, and community-focused organisations of all kinds. Their shared goal is promoting a "donation-friendly America" by fostering donation education and creating opportunities for individuals to sign up to save lives through organ and tissue donation.</p> <p>Workplace Partners make a commitment to educate their employees, members, and/or customers on the critical importance of blood, bone marrow, and organ and tissue donation and join to provide opportunities for people to register as donors. Workplace Partners join with HRSA and local donation organisations and other groups to help educate their constituents about organ and tissue, blood and bone marrow donation.</p> <p>One key strategy is ‘Give 5—Save Lives’. Workplace Partners select one to three dates and give employees five minutes during those work days to sign up to become donors. Workplace Partners use or customise materials and tools such as email blasts, fact sheets, newsletter articles, and Web banners available from HHS to encourage donation in their workplace.</p> <p>An academic study of these initiatives in the early 2000s found that the use of organ donor collateral in the workplace could improve the organ donation rate by 13.6%. Personal intervention increased rates above this. (See <i>Organizations as Communities: Creating Worksite Campaigns to Promote Organ Donation Susan E. Morgan Purdue University, USA</i>)</p>	http://organdonor.gov/howhelp/workplace.html
Donate Life California	“Rose Parade Float” (Ongoing)	Every year, Donate Life enters a float into the California New Year Rose Parade to honour their donors. The float has a different design every year. Transplant recipients are selected to ride on the float. Memorial ‘floragraphs’ (artistic portraits) of donors are also featured.	http://www.donatelifefloat.org/prod/components/
Donate Life America	“Cheryl's Cookie Card” (2013)	<p>In 2013 a partnership was established between Cheryl's Cookies and Donate Life America.</p> <p>The partnership has created 'Donate Life Cheryl's Cookie Card'. The card (costing \$5) allows people to send a friends, colleagues or family members a cookie inside a 'donate life' box. The box also comes with a personalised message, and a reward card (\$5 worth) to use on a future purchase. For every card sold, 10% of the purchase price goes to Donate Life America.</p>	http://donatelifenet.org/cherylscookies/ http://www.cheryls.com/donate-life-cookie-card-cco-sp14-128941?categoryId=400095997
Facebook	Facebook and Organ Donor Status (2013)	<p>In May 2013, Facebook announced that users could post their organ donor status to their Facebook Timelines as they had made registering “a life event”.</p> <p>To see whether this strategy was effective in boosting donor rates, researchers from Johns Hopkins University School of Medicine in Baltimore analysed US online donor registration activity in state registries during the initial weeks following the start of Facebook's project. The researchers found that during the weeks after the initiative launched there was a significant uptake in donor registration in all states. On the first day of the launch there, were 13,054 new online registrations — a 20-fold spike from the prior average of 616. Notably six times as many people registered on the first day of the Facebook feature in Michigan. and there was a 108-fold increase in Georgia. (Time Magazine, June 18, 2013)</p>	https://www.facebook.com/help/organ-donation http://www.bloomberg.com/news/2013-06-18/facebook-s-organ-donor-status-spurs-boost-in-awareness.html
Donate Life New York	“Hate the Wait” (2013)	This integrated campaign sought to encourage New Yorkers to join the ODR. The materials were based on the cultural assumption that New Yorkers hate to wait in line, and used the local message that every 15 hours a New Yorker dies waiting in line for an organ.	http://www.donatelifeny.org/hate-the-wait-campaign/ http://www.donatelifeny.org/hate-the-wait/
DonateLife	“Twenty million in 2012 campaign”	This 2012 activity used the strapline 'twenty million in 2012' and featured across most of the campaign materials for the year. Different Donate Life branches ran their own campaigns to push the message forward and to target areas on a local level. There were also four national Donate Life events, including a Flash Mob and a fashion show.	http://donatelifenet.org/20million/

Richland Community College	“Life goes on” (2011)	<p>In 2011, Richland Community College ran on-campus activity around organ donation to tie in with Illinois’ Secretary of State’s “Life Goes on” organ donation campaign.</p> <p>Posters and daily postings on Facebook and Twitter were all themed with the campus campaign theme of “Help life go on.”</p> <p>Videos were created in-house featuring students, faculty, and staff whose lives have been directly touched by a donor and were then posted on YouTube and shown on campus-vision. Each person in the video was then highlighted in specific marketing pieces throughout the campus and in a prominent display case in the Mueller Student Centre. A sign up booth was set up in the student centre and staffed during the week of the campaign.</p> <p>The College’s goal of 100 new “donors” was successfully met and the campaign’s final tally was 130 new “donors” in five days.</p>	http://www.richland.edu/marketing/donatelife
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2: Summary of key sources

The sources in the summary table below have been listed and detailed chronologically (as per the list below), according to date published or created. For example, if data tables have been created specifically for 23red they are dated according to the date they were received.

Contents covered in summary table

• NHSBT PDA and ODR data	2009-2013
• NUH Deceased Donation Data, Nottingham University Hospitals	Feb 2014
• What are effective approaches to increasing rates of organ donor registration among ethnic minority populations? A systematic review, Sarah Deedat, Charlotte Kenten, Myfanwy Morgan	Dec 2013/Jan 2014
• International Figures on Donation and Transplantation, 2012, Global Observatory on Donation and Transplantation	Jan 2014
• Reaching out to the local community, Jack Adlam, Deputy Head of Communications, Sherwood Forest Hospitals NHS Foundation Trust	Jan 2014
• Applying Behavioural Insights to Organ Donation: preliminary results from a randomised controlled trial, Behavioural Insights Team, Cabinet Office	Dec 2013
• 7 Circles of influence: Normalising Conversations around Organ Donation in BAME Communities, Sharon Platt-McDonald	Dec 2013
• BHF Organ Donation Policy Statement	Dec 2013
• Faith engagement and organ donation action plan – Gurch Randhawa	Nov 2013
• Scotland Campaign briefing pack, 2013/14	Nov 2013
• Organ donation: Public attitudes and stakeholder engagement in Northern Ireland 2013	Oct 2013
• Public attitudes on organ donation – The need for change, Terence Foster	Oct 2013
• The emergence of the ‘ethnic donor’: the cultural production and relocation of organ donation in the UK Ciara Kierans & Jessie Cooper, Anthropology and Medicine	Oct 2013
• What do Opinion Polls tell us? Ben Page presentation at National Donation and Transplantation Congress	Sep 2013
• Optimisa Research: NHSBT Organ Donation 2013 research: Understanding current attitudes and behaviours towards organ donation within England	Aug 2013
• BAME Organ Donation Educational Activity	Aug 2013
• National Transplant Week 2013 Evaluation (8th – 14th July)	Aug 2013
• Bereaved families experiences of organ and tissue donation and perceived influences on their decision making, Sque et al, 2013	Jun 2013
• Public Perceptions of the NHS and Social Care, An Ongoing Tracking Study Conducted for the Department of Health, December 2012	Jun 2013
• Human transplantation Wales Bill, Explanatory Memorandum incorporating the Regulatory Impact Assessment and Explanatory Notes	Jun 2013
• Organ donation and transplantation activity report 2012-2013	May 2013
• Dying: Discussing and planning for end of life, British Social Attitudes 30, Janet Shucksmith, Sarit Carlebach and Vicki Whittaker	May 2013
• Potential Donor Audit NHSBT 2012-2013	April 2013
• A Randomised Controlled Trial to Test if a Simple Anticipated Regret Manipulation Leads to a Significant Increase in Organ Donor Registrations Prof R O’Carroll Prof. E. Ferguson, Prof. P.C. Hayes, & Dr L. Shepherd	April 2013
• ICM Research, Organ Donation	Mar 2013
• Organ Donation Campaign Evaluation Scotland – TNS	Feb 2013
• Draft Engagement Strategy, BAME & Faith Groups, Human Transplantation (Wales) Bill	Jan 2013

• Remember a Charity Impact Report	2013
• Opt-out systems of organ donation: International review of evidence, Melissa Palmer, Welsh Government Social Research	Dec 2012
• Public attitudes to organ donation: Baseline survey 2012 (Wales)	2012
• NHS Organ Donor Register Research Scotland NHS	Aug 2012
• Scottish Organ Donor Register (SODR): Historic Benchmarking & Trend Review	Aug 2012
• Scottish Organ Donor Register DM Campaign Evaluation	May 2012
• Organizations as Communities: Creating Worksite Campaigns to Promote Organ Donation, Susan E. Morgan, Purdue University, USA	Feb 2012
• Opt-out systems of organ donation: International evidence review, Welsh Government Social Research	2012
• KPMG report: Strategic Evaluation of the ODR	Aug 2011
• KPMG PowerPoint, Organ Donor Register Public Engagement Study for KPMG and NHSBT, BDRC Continental	Aug 2011
• Organ Donor Register: When it is better to receive than to give: Ila De Mello Kamath & Bridget Angear	2011
• Public awareness of and support for organ donation in the UK: guiding communication, Synovate	2009
• The Intersection of Conversation, Cognitions, and Campaigns: The Social Representation of Organ Donation, Susan E. Morgan <i>Communication Theory</i>	2009
• Why relatives do not donate organs for transplants: ‘sacrifice’ or ‘gift of life’? Magi Sque, Tracy Long, Sheila Payne & Diana Allardyce	Sep 2007
• Scottish Executive – Life after death: the difficult business of signing people up to organ donation, IPA paper, Giles Moffatt, Dr Stephen Tagg and Gillian Govan	Sep 2007
• BAME barriers to organ donation	No date
• Paula Aubrey Executive Summary of PHD	No date

Title of Research and Author	Date published/obtained	Contents	Key Learnings	Methodology
NHSBT PDA and ODR data 2010-2013	Jan 2013	<p>The NHSBT PDA and ODR teams supplied a series of raw data sheets on each stage of the donor journey (identification, family approached, family consented, donation) cross broken against key demographic and situational variables such as:</p> <ul style="list-style-type: none"> Gender Age Ethnicity Region ODR status Other methods of expressing donation wish Type of death <p>Separate data sheets and graphs were supplied on:</p> <ul style="list-style-type: none"> Refusal reasons Relationship of next of kin consent rates 	<ul style="list-style-type: none"> Eligible donors (2009-2013 data) <ul style="list-style-type: none"> Aged 35-69 (27% are 60-69, 22% are 50-59, 19% are 35-49) White Dead from stroke From the Midlands Eligible donors who are approached (2009-2013 data) 35-69 (25% are 60-69, 24% are 50-59, 23% are 35-49) White From London Actual Donors (2009-2013 data) <ul style="list-style-type: none"> Aged 35-69 (24% are 60-69, 24% are 50-59, 24% 35-49) White Dead from stroke From London Age and consent rates (2009-2013 data) 0-17 46% 18-24 60% 25-34 61% 35-49 60% 50-59 57% 60-69 56% 70+ 54% Expressed wishes and consent rates (2010-2013) 96% consent rate when wishes have been expressed verbally 96% when on the ODR have a donor card and have expressed verbal consent 95% donor card and verbal 93% ODR and verbal 83% ODR and donor card 77% donor card 	This data is collected through the Potential Donor Audit and the data that is held by the Organ Donation Register

			<ul style="list-style-type: none">• 71% ODR <ul style="list-style-type: none">• Religion consent rates (2010-2013)• 68% Other• 65% None• 61% Christian• 58% Jewish• 56% Hindu• 55% Unknown• 55% Buddhist• 35% Jehovah's Witness• 35% Sikh• 8% Muslim <ul style="list-style-type: none">• Refusal Reasons (The most common reasons in the 2009–2013 data)• 17% Patient had stated in the past that they did not wish to be a donor• 15% Family were not sure whether the patient would have agreed to donation• 12% Other• 10% Family felt the length of time for donation process was too long• 9% Strong refusal – probing not appropriate• 8% Family did not want surgery to the body• 7% Family felt the patient had suffered enough• 6% Family were divided over the decision• 5% Family did not believe in donation• 5% Family felt it was against their religious/cultural beliefs• 3% Family felt the body needs to be buried whole (unrelated to religious or cultural reasons) <ul style="list-style-type: none">• Gen pop vs ODR vs Donors (2012-2013)<ul style="list-style-type: none">– AGE: More of the older age groups in donor population than there are in the ODR population and the general population.– BAMEs: There is a greater proportion of BAMEs in the UK pop (13%) than are on the ODR (4%) or within the donor pop (5%).– ACORN: There are more Hard Pressed people in the donor pop (23%) compared to the ODR (16%) and UK pop (18%). There are slightly fewer of the wealthier groups in the donor population. <ul style="list-style-type: none">• ODR sign up channels<p>On the whole, the DVLA is the most popular way to sign up to the ODR. However, when looking at the proportion of particular demographics within a sign up channel it can be seen that:</p><ul style="list-style-type: none">• Slightly more men sign up through the DVLA than women. Other channels have slightly more women signing up.• Of those that sign up by leaflet or Organ Donor line they are slightly more likely to be in the older age groups.• As ethnicity is not recorded by the DVLA, the demographic pattern here is less clear cut.	
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NUH Deceased Donation Data, Nottingham University Hospitals	Data was supplied in Feb 2014 but actually compares Apr – Aug 2012 with Apr – Aug 2013	This data compares the number of Referrals Refusals Consents Transplant recipients in a five month period in 2012 and in a five month period in 2013 in which the Be a Hero campaign on organ donation ran	The periods compare as follows: 72 referrals during the period in 2013 compared to 33 during the period in 2012 21 consents in 2013 vs 7 in 2012 35 transplant recipients in 2013 vs 16 in 2012 These are updated results on those contained in the Jan 2014 presentation Reaching out to the local community also detailed in this summary.	Nottingham University Hospital Data
What are effective approaches to increasing rates of organ donor registration among ethnic minority populations?: a systematic review, Sarah Deedat, Charlotte Kenten, Myfanwy Morgan	Dec 2013/Jan 2014	A literature review which aims to identify effective interventions to increase organ donor registration and improve knowledge about organ donation among ethnic minorities in North America and the UK.	Mass media interventions alone reported no significant change in the intention or willingness to register. Educational interventions either alone or combined with mass media approaches were more effective in increasing registration rates with a strong interpersonal component and an immediate opportunity to register identified as important characteristics in successful change. Effective interventions need to be matched to the populations' stage of readiness to register. Measured outcomes should include registration and shifts along the pathway to this behavioural outcome.	Literature/Research Review
International Figures on Donation and Transplantation, 2012, Global Observatory on Donation and Transplantation (A separate database, Irodat also consulted for international figures on donor numbers)	Jan 2014	Worldwide figures on transplants and refusal rates	Amongst the data is this comparison of refusal rates across the world: Turkey 76.6% UK 42.5% Australia 41.8% Italy 26.1% Spain 15.6% Poland 11.2% Hungary 6.2%	Compiled from official national statistics
Reaching out to the local community, Jack Adlam, Deputy Head of Communications, Sherwood Forest Hospitals NHS Foundation Trust	Jan 2014	Presentation given on Jan 16 th explaining the activities of the Be a Hero organ donation campaign	Presentation explains how this campaign used <ul style="list-style-type: none"> • Local and regional media • The local community • Face to Face • Brand building The presentation does outline results. However, updated results were supplied in Jan 2014 as detailed above.	Nottingham University Hospital Data

Applying Behavioural Insights to Organ Donation: preliminary results from a randomised controlled trial Behavioural Insights Team, Cabinet Office	Dec 2013	Results of a randomised controlled trial into different messages on the Golden Page of the DVLA that could prompt people to join the Organ Donation Register.	<p>The best performing message was one of reciprocity and fairness: “If you needed an organ transplant, would you have one?”</p> <p>The next best performing message was one about death: “Three people die every day because there are not enough organ donors.”</p> <p>1,203 more people registered under the best performing message. The paper calculates that this difference would lead to approx 96,000 additional registrations in one year.</p>	Randomised controlled trial
7 Circles of influence: Normalising Conversations around Organ Donation in BAME Communities By Sharon Platt-McDonald	Dec 2013	<p>This paper looks at what the circles of influence may be with regards to BAMEs and their views on organ donation.</p> <p>The phrase ‘circles of influence’ in relation to organ donation was coined as a way of augmenting NBTA Communications Strategy to include the way they communicate the message of organ donation to varying entities and people groups.</p>	<p>These are the circles of influence posited in the paper:</p> <ul style="list-style-type: none"> • 1st circle – the inner circle – family members; • 2nd circle – the next circle which is slightly larger would be significant others, e.g. guardians, (foster parents), friends, (peers) professional contacts • 3rd circle – next circle would be larger still and could represent the education and faith communities e.g. educational institutions (schools, colleges, universities), faith groups (churches , mosques) • 4th circle – health institutions, e.g. primary and secondary healthcare establishments (hospitals, clinics) • 5th circle – after that a larger circle could be voluntary agencies • 6th circle – then government agencies, e.g. DOH, DOE • 7th circle – general public – national messages via media (TV, newspaper, radio, social networks etc.) 	Not outlined
BHF Organ Donation Policy Statement	Dec 2013	BHF policy statement	<p>BHF support an opt-out system of organ donation but: “An opt-out system must be sufficiently robust to ensure that everyone who wishes to opt out has the opportunity to do so, and close family members should be consulted at the time of organ retrieval. Any changes to the system should be accompanied by a wide-ranging communication strategy to engage with people from a range of communities. It’s vitally important that people let their families know their wishes so that these are clear and respected after they die.”</p> <p>The document then analyses the current environment within which organ donation takes place and any changes that would need to happen to support an opt-out system. This includes:</p> <ul style="list-style-type: none"> • Public awareness and media engagement • Training of staff • A national agency • Transplant co-ordinators • Management of donors • Removing financial barriers for hospitals • Transplant centres and donor hospitals • Critical care beds 	

Faith engagement and organ donation action plan – Gurch Randhawa	Nov 2013	<p>This document provides an action plan to actively engage UK faith communities with issues surrounding organ donation.</p> <p>The strategy is based on:</p> <ul style="list-style-type: none"> • The objectives of the NHSBT ‘Taking Organ Transplantation to 2020...’ document • Existing academic and government research • Themes derived from discussions with faith leaders at the Faith and Organ Donation Summit in 2013. 	<p>The themes arising from the Faith and Organ Donation summit were:</p> <ul style="list-style-type: none"> • More engagement is needed • There is a need to engage at a local level • There is an opportunity to engage those working in the health services • The debate needs to engage people at many levels • Greater resources will be needed to achieve greater engagement <p>Key strategic principles agreed at the summit were:</p> <ul style="list-style-type: none"> • Faith leaders would display commitment to organ donation and support community-level communications. • Work with NHSBT and take on spokesperson roles encouraging debate on organ donation via communication channels available through their faith/local community. • To be available, where convenient, for interview by the national/regional media in specialist titles. • Become faith ambassadors for organ donation to include proactively seeking opportunities (e.g. faith-led events, media partnerships) within their organisation/s to promote organ donation and facilitate debate amongst their supporters/local communities. • To identify possible support required from NHSBT such as financial support or helping gain access to/appeal for case studies to assist with faith outreach. • To work internally within their communities to clarify issues relating to definitions and diagnosis of death (with the support of NHSBT where necessary). 	NA
Scotland Campaign briefing pack 2013/14	Nov 2013	<p>Briefing on how the Wee Chat campaign is going to progress and develop</p>	<p>During a five-year period to March 2013, Scotland saw a 74% increase in donors, as well as a 36% increase in transplants with deceased donor organs.</p> <p>The number of Scots on the NHS Organ Donor Register has also increased from 29% in 2007/8 to over 41% at the end of 2012/13 – by far the highest percentage of any of the four UK countries.</p> <p>The paper states that authorisation rates are being seen as the true measure of success, therefore a campaign was developed to highlight the importance of talking to family about donation wishes. Its success is highlighted by the fact that figures over the past five years show as many as 62% of donors were not on the Register at point of death. Although the primary aim of the new campaign was not solely to drive registrations, figures showed that as well as increasing discussion and debate about donation, the campaign still continued to generate sign ups to the Register.</p> <p>From launch through to end of March 2013, the new website converted 23% of all unique site visitors to registration, representing over 8,480 sign ups during the campaign period.</p> <ul style="list-style-type: none"> • 43% of people landing on the registration page completed the sign up process; • Across all channels, 1,205 people texted, which converted into 760 sign ups; • Field activity generated 5,130 sign ups over an 80-day period, with 12,771 pledges; • A successful PR campaign which generated almost 300 pieces of print and broadcast coverage. <p>The campaign started again in Oct 2013. Along with TV, radio, field roadshow activity, digital and PR, the home page of the Organ Donation Scotland website – www.organdonationscotland.org – will give greater prominence to the Supporters’ Wall, where people can give the reasons behind their decision to join the NHS Organ Donor Register.</p> <p>Facebook will also be utilised in the campaign due to be included as well as GP surgeries.</p>	Not outlined

Organ donation: Public attitudes and stakeholder engagement in Northern Ireland 2013	Oct 2013	<p>Research into:</p> <ul style="list-style-type: none"> Public attitudes towards organ donation Public knowledge of the donation process Families and knowing organ donation wishes of a loved one <p>There is also research into stakeholders' views on these areas.</p> <p>This research was undertaken with the view to inform the direction of a public campaign.</p>	<p>Stakeholder opinion:</p> <ul style="list-style-type: none"> • Informs the public by providing correct information and dispelling myths, e.g. 45% responded 'true' or 'did not know' to the statement 'It is possible for a brain dead person to recover from their injuries' • Educates the younger generation • Public campaign should focus on discussing donation wishes with your family/friends • Testimonial approach was considered effective in conveying memorable messages • Facts, figures or messages given in a public information campaign should be positively framed, i.e. focus on the number of lives that can be saved from donation rather than the number of people who die while waiting on a transplant. <p>Recommendations from public attitudes survey:</p> <ul style="list-style-type: none"> • Increase awareness and knowledge of organ donation • Increase awareness of the ODR • Mobilise people who are currently ambivalent about donation • Encourage people to discuss their donation wishes with their family/friends <p>Both the public attitudes survey and the stakeholder engagement process highlight that a key focus of a campaign should be to encourage the public to discuss their donation wishes with family/close friends.</p>	<ul style="list-style-type: none"> • 1,012 member of NI general population interviewed face-to-face in their homes • Stakeholder surveyed through focus groups and pro forma engagement (clinicians, nurses, SNODS, sisters, charities, those on the waiting list, transplant recipients and donor families)
Public Attitudes on Organ Donation – The Need For Change, Terence Foster	Oct 2013	<p>A discussion paper created by Terrence Foster – its focus is on persuasion about organ donation through medical expertise.</p>	<ul style="list-style-type: none"> • Identifies that there is a fear of mutilation around organ donation • There needs to be attitudinal change but Foster suggests this will come from the adults of tomorrow and from educational programmes • Those who have received donations should become advocates 	

The emergence of the ‘ethnic donor’: the cultural production and relocation of organ donation in the UK, Ciara Kierans & Jessie Cooper Anthropology and Medicine	Oct 2013	<p>This paper draws attention to the ways in which ‘ethnicity’ has been made problematic by the allocation practices of transplant medicine, health promotion discourses and policy developments.</p>	<p>The research found that approaching families to ask their consent was understandably regarded as difficult and anxiety provoking.</p> <p>When the family is from a minority ethnic background, the task is seen as particularly sensitive and problems were anticipated from the outset.</p> <p>Non-white skin colour, the presence of religious objects, dress, language and the gathering of large numbers of family members were treated as foreshadowing possible difficulties. Ethnicity was a problem made in advance.</p> <p>Research also pointed to how SN-DOs and CLODs etc. might have experienced and/or anticipated difficulties in form filling with ethnic minority families. Some talk about next of kin leading their lives differently to how their family perceived them to be behaving.</p> <p>There are no good grounds for thinking that white families do not encounter the same type of problems, have similar complex fears around the death of their loved-ones or indeed present challenging scenarios for those tasked with organ procurement.</p> <p>The researchers’ claim the need for differential treatment is simply pre-written into donation processes and the particulars of given encounters are then treated as evidence that this differential treatment around ethnicity was warranted.</p> <p>Transplant medicine not only enacts the populations it depends on, it produces them through its own classificatory practices, formal and informal (Ruppert 2011).</p>	<p>Multi-sited ethnographic fieldwork conducted between October 2009 and February 2011 in two acute hospital Trusts in the North of England, serving large Indian and Pakistani populations. Data was gathered from ethnographic interviews; observations of donor nurse team meetings, donation training for health professionals, organ donation committee meetings, and in various ‘community’ settings (e.g. religious temples and community centres); alongside narrative interviews with health professionals involved in requesting organs from these same populations, and wider community members with experience of transplantation.</p>
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<p>What do Opinion Polls tell us? Ben Page presentation at National Donation and Transplantation Congress, Sep 2013</p>	<p>September 2013</p>	<p>This presentation has been put together to question whether 90% of the population truly agree with organ donation.</p>	<p>This presentation shows data from a 2010 IPSOS study which indicates that 62% of the public are either Fairly Likely, Very Likely or Certain to donate their organs, which questions whether people are as approving of organ donation as they claim.</p> <p>Of those that did not want to donate their organs, 28% said this was simply because they did not want to.</p> <p>27% of all those that did not want to donate their organs said they might do if it was for a family member.</p> <p>The presentation goes on to say that thinking about death is the key barrier to considering registering. Death has meaning for yourself, your body and your family and the presentation maps some key concerns against the types of people who are likely to have them and also maps them against the positions of disengaged, think, talk and act.</p> <p>The presentation also explains that there is a pathway we follow when we make rational decisions but when we make irrational decisions we skip these stages.</p> <p>It is posited that there are four levers that can be used to guide behaviour: Hug Smack Nudge Shove OR Inform Enable Incentivise Enforce</p> <p>Successful behaviour change campaigns use all levers.</p> <p>The presentation also suggests that: Anchoring Social Norms Reciprocity</p> <p>can be utilised.</p> <p>Successful campaigns need to position themselves in the following ways: “It’s about me and my world vs it’s about others” “Personal choice vs authoritative tone” People from BAME backgrounds need evidence that directly relates to their ethnic background/religion and community</p> <ul style="list-style-type: none"> • Provide information: Patients from the same ethnic group are more likely to be a close match; • Make a personal connection: People from some BAME communities are more likely to develop diabetes or high blood pressure; • Create urgency: Donor rates are relatively low but the need for donor organs is high amongst some BAME communities. <p>Getting people talking is critical.</p>	<p>Evidence drawn from IPSOS Mori data</p>
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<p>Optimisa Research: NHSBT Organ Donation 2013 research: Understanding current attitudes and behaviours towards organ donation within England</p> <p>(Optimisa research June 2013 short presentation is a shorter presentation of this.)</p> <p>Data tables have also been provided</p>	<p>Aug 2013</p>	<p>Research into: Public awareness and attitudes (and BAME views within that) of</p> <ul style="list-style-type: none"> organ donation ODR and donor cards need for next of kin consent <p>There is also research into stakeholders' views on these areas.</p>	<ul style="list-style-type: none"> Create more conversation around organ donation and highlight how much of society is broadly in favour of it The personal benefit of organ donation needs to be highlighted as against the societal benefits of organ donation The concern that medical staff may not do their best to save a life if the person is an organ donor needs to be addressed Opportunity to challenge misconceptions around potential donor ages There are lower levels of awareness and support for organ donation amongst BAME communities Muslims and those from a Pakistani or Bangladeshi background are more likely to raise religious objections to organ donation. Those from Black groups are more likely to voice a mistrust of the NHS. There needs to be more promotion of organ donation from within these communities. Further promotion of ODR and addressing misconceptions around it need to be addressed Potential to bring back donor cards Increase awareness that next of kin will be asked for consent and therefore this issue needs to be discussed before death. Respondents displayed similar hypothetical levels of willingness to allow a loved one to be used as an organ donor if they had either hypothetically signed the ODR or had discussed their wishes with others. In hypothetical situations where neither of these factors existed, respondents were less likely to say they would go on to donate their loved ones' organs. The paper does go onto to propose that where someone is on the organ donor register, the families should be informed of this rather than so explicitly asked for consent. Stakeholders gave similar views in their interviews. They believed that: <ul style="list-style-type: none"> Discussions around organ donation need to take place before death Schools may have a place in educating people about organ donation There needs to be a greater demographic variance in SNODs; they tend to be white and female Families, particularly those with religious views, need to be reassured that the body is treated with respect during the organ donation process Some SNODs and CLODs felt their work was somewhat isolated and not joined up with other medical departments. 	<ul style="list-style-type: none"> 24 interviews with couples 14 family triads Quant survey to 1,007 people and boost survey to 542 people from BAME groups 6 interviews with clinicians 4 interviews with charities
<p>BAME Organ Donation Educational Activity</p>	<p>Aug 2013</p>	<p>Evaluation of BAME activity 2012/2013</p>	<p>BAME activity in 2012/2013 aimed to:</p> <ul style="list-style-type: none"> reduce the propensity for relatives of potential BAME donors who have not expressed their wishes to withhold their consent. increase awareness and support about the lack of donors in the Black and Asian communities and challenge the misconceptions surrounding organ donation. increase registrations from the Black and Asian communities, thereby increasing the number of organs available for transplant. <p>The primary audience was Black and Asian communities who live in London and Greater London. Over 90% of BAME organ donors currently come from the capital. The secondary was Faith leaders, faith networks, key BAME stakeholders and partners nationally. Key leaders and influencers have pledged support for organ donation and will disseminate key messages amongst their congregations and followers.</p>	<p>Not outlined</p>

			<p>Past campaign analysis shows that faith roadshows continue to be an effective channel for communication. It was decided to continue with a series of faith events in key areas with a high percentage of the target audience.</p> <p>Activity carried out at places of worship was implemented over a 12-week period and included at least 3 visits to each of the faith centres (a pre-event visit to put up posters promoting the roadshow and encouraging recipients and those in need of an organ to attend and share their stories; the roadshow itself, and a post-event evaluation). This aimed to promote a longer term relationship with individual faith leaders at centres and congregations and allowed the opportunity for people to go away and discuss it with their families and come back and discuss organ donation again at a later date. This also provided a chance to address any further concerns identified and evaluate behaviour change as a result of the roadshow.</p> <p>The faith roadshows maximised impact and traction by galvanising relevant faith leaders and faith champions to help facilitate, promote and provide positive messages for these events. Support was also leveraged from SNODs where possible and organ donation recipients who responded to poster campaign were encouraged to attend and support. Faith leaders were also invited to identify members of their congregation who have been touched by organ donation or who have their own personal stories that they are willing to share.</p> <p>Outcomes There were 28 BAME events in London and Greater London between February and May. These took place at 6 Black Churches, 11 Gurdwaras, 3 Temples, 5 Mosques and 3 other events or religious festivals.</p> <ul style="list-style-type: none"> • Gurdwaras did 11 events generating 939 responses • Churches did 6 events generating 209 responses • Temples had 3 events generating 223 responses • Mosques had 5 events generating 6 responses • There were 2 Asian melas which generated 218 responses <p>Post event evaluation showed that of those who were already signed up to the ODR or who signed up as a result of the faith roadshow, 60% would not discuss their wishes with their family. Evaluation also found that, out of the 201 people who took the questionnaire, 78% did not know whether they would donate if a loved one had not shared their wishes about organ donation, whilst 10% said they would and 11% said they would not. In comparison, if they were aware of their loved one's wishes 60% would agree to donation, 33% weren't sure and less than 1% would say no. This supports the findings from the recent Optimisa Market Research.</p> <p>As a result of the faith roadshow, there were 1,304 responses from the Asian community, 208 from the Black community and 4 from the mixed community. In total there were 1,516 BAME responses as a direct result of this activity from 28 events.</p>	
National Transplant Week 2013 Evaluation (8th – 14th July)	Aug 2013	<p>Evaluation of campaign in 2013 The objective of National Transplant Week itself was to:</p> <ul style="list-style-type: none"> • raise awareness of the issue of organ donation and get people talking about it • encourage people to champion the issue of organ donation with family and friends and share their donation wishes to help increase consent rates • get people to act and sign up to the ODR – aim for 15,000 responses 	<p>'Pass it On' was adopted as the theme for a second year. Activity included</p> <ul style="list-style-type: none"> • 'Organ donation Through A Lens' – national film competition: • 'A little more conversation' celebrity films: • Donate Life Concert <p>Impact on the NHS Organ Donor Register</p> <p>Channel Responses 2013 Online total 17,646 NTW site 1,413 ODT site 16,153 Asda 80 Leaflet total 2,491</p>	Not explicitly outlined but assume digital and social media tracking

			<p>Generic 1,392 NTW 1041 Asda 58 Calls 199 Facebook 66 Text total 58 NTW 8 Generic 47 TOTAL 20,460</p> <p>The majority of sign ups were via the organdonation.nhs.uk website (16,153 sign ups). There were only 1,413 sign ups via transplantweek.co.uk. When the document was created, the total number of registrations for NTW (conversions from responses) was still to be fully calculated.</p> <p>There were 629 pieces of media coverage achieved for NTW 2013 compared with 241 pieces in 2012.</p> <p>In terms of media coverage distribution across the UK, the North West was the most prominent region (13%), with awareness-raising activities by local NHS trusts and case study placement.</p> <p>75% of all mainstream media content featured at least one key message. ‘Pass it On: Talk to those closest to you’ was the leading message resonating across 48% of all mainstream articles.</p> <p>Reach to all UK adults increased on the previous year, rising from 69% to 80%. OTS also rose considerably, with the average number of exposures to UK adults rising from 2.4 to 9.3. This was most in part due to higher volumes of coverage generated by the campaign, with audiences being more frequently exposed to a broader range of publications including national titles which rose by 113% year-on-year.</p> <p>On Facebook there was a high level of engagement and reach with a combination of fan, celebrity and created content (infographics and twibbon) contributing to elevated discussion. The NHSBT page grew by 1,768 supporters during the week, compared to 440 in 2012, an increase of 301%. 28 posts were uploaded from a prepared content plan. These posts were liked a total of 9,484 times (average 339 each) and this, alongside shares and comments, contributed to NTW posts reaching users newsfeeds a total of 906,715 times in the week.</p> <p>There were a total of 5,987 shares of these 28 posts in the week, compared to 1,798 in 2012. Twitter grew by 242 followers during the week (currently 11,439 followers). There were a number of high level influencers tweeting; Caitlin Moran (429,000 followers at time of tweet) and Edith Bowman (236,181 followers) tweeted of their own accord and evoked the most engagement, along with Richard Branson (3,403,797 followers). Alexandra Burke and Alesha Dixon followed with most engaged tweets. A number of organisations also tweeted including fleshandblood, Transplant Games, LLTGL, British Liver Trust, ASDA, Donate Life, ACLT and various Trusts.</p> <p>NHSBT’s partnership with ASDA saw 500,000 bags for life sold at stores across the UK and promotion to their near one million Facebook fans. Sally Johnson also attended a staff event at ASDA HQ to help promote the new partnership. Virgin promoted NTW through its digital platforms and Richard Branson supported the celebrity film activity.</p>	
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Bereaved families' experiences of organ and tissue donation and perceived influences on their decision making, Sque et al, 2013	June 2013	Investigation of bereaved families' experiences of organ and tissue donation and the influences they perceive as affecting their decision making.	<p>The majority of families suggested that they were aware of their relative's wishes regarding donation. They were motivated to fulfil those wishes. There were also comments about donation being a positive moment in a tough time.</p> <p>Some comments were made about the PDA form and how people found it quite distressing, especially questions about whether their relative could have slept with another man (if they were a man and not known to be gay). Promoting what a family organ donation interview is like will help create understanding about what might be asked. Sometime interviewees seem to struggle to fully understand DBD and DCD.</p> <p>The feeling that the deceased's body needs to be protected is a key theme.</p> <p>Length of time to donate is a key distress point for families as well as people dying slowly.</p> <p>Sque herself further recommends ethnography.</p> <p>Families were unsure about receiving acknowledgement and praise but liked the idea of tribute to the deceased. However, if recognition helped promote organ donation they were up for it. But overall more people were against public recognition.</p> <p>There were mainly positive reports about receiving correspondence from recipients but this was tinged with sadness.</p> <p>Tributes could include a personalised key ring for family and friends, a commemorative bench, tree planting, web page, book of remembrance or memorial trophy.</p> <p>There also appeared to be a role for post donation aftercare.</p> <p>In conclusion the key recommendations put forward are:</p> <ul style="list-style-type: none"> • Need for public education strategies which get people to talk about donation • Public education should include what is actually involved in the moment of decision, the form etc. • The donor family interview needs to be more person-centred and less task-orientated • Importance of donor family room • There needs to be specific information about eye donation • The pathway of DCD needs to be investigated to inform potential donor and family care • Research needed to investigate association between positive family care and donation consent • Donation service should work with SNODs to identify ways in which family support and communication could be optimised • The role of the SNOD post donation should be reviewed to establish responsibility for the care offered to bereaved families • The study also suggested that there needs to be research into examining the role of young people and children in donation decisions. 	<p>Retrospective interviews with 43 participants from 31 families. Their next of kin had died an average of seven months before the interview.</p> <p>The study had originally aimed to talk to people who had refused donation, but they could not be recruited.</p>
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Public Perceptions of the NHS and Social Care An Ongoing Tracking Study Conducted for the Department of Health, December 2012 Wave	June 2013	<p>The aim of the survey is to explore public attitudes towards, and perceptions of, the NHS and social care services, and to provide a means of tracking these perceptions and attitudes over time.</p>	<p>People in social grades D/E are more likely to say that they are dissatisfied with the running of the NHS than people overall (18% compared with 13% overall).</p> <p>Those aged 65 or over are more likely than others to agree that Britain’s NHS is one of the best in the world (82% compared with 77% overall), as are people in social grades A/B (82% agree).</p> <p>People in social grades A/B are more likely to agree that people are treated with dignity and respect when they use NHS services (73% compared with 67% overall). Those aged 65 and over are more likely than others to strongly agree with this statement (21% compared with 16% overall).</p> <p>When asked “Thinking back to the last time you saw a health professional, such as a GP or hospital doctor, to what extent would you agree or disagree with each of the following statements? I was involved as much as I wanted to be in decisions about my care or treatment.”</p> <p>People aged 16 to 24, and those in social grades D/E are more likely to say that they were not as involved as they wanted to be in decision making (18% and 14% disagree respectively, compared with 11% overall).</p>	<p>All interviews were carried out by IPSOS MORI interviewers in respondents’ homes, using Computer Assisted Personal Interviewing (CAPI). A total of 1,001 interviews were conducted with adults aged 16 and over in England between 5 November and 16 December 2012.</p> <p>In order to achieve a sample representative of the national and regional population, quotas were set for the number of interviews carried out with different types of respondents. Quotas were set for age, gender and working status.</p>
Human Transplantation (Wales) Bill: Explanatory Memorandum incorporating the Regulatory Impact Assessment and Explanatory Notes	June 2013	<p>This paper was published to explain various aspects around Wales’ Human Transplantation Bill.</p>	<p>The paper outlines key technical aspects to presumed consent – how wishes will be registered etc.</p> <p>The paper also explains how the potential increase of 25% has been calculated. It is based on the work of Abadie and Gay in <i>The impact of presumed consent legislation on cadaveric organ donation: A cross-country study, Journal of Health Economics, 2006</i>. In this study it was calculated that “opt-out systems can improve organ donation rates and suggest donation rates in countries with opt-out type systems can be 25 to 30 per cent higher compared with countries where other systems are in operation.”</p> <p>The paper then calculates how an increase of 25-30% might impact Wales: “An increase of 25% from a base of 65 donors (this is the number of Welsh residents who died in Wales and donated organs in 2011/12) would be equivalent to approximately 15 additional donors. 15 additional donors with associated increases in transplantation rates would generate an NPV of approximately £147 million.”</p> <p>In a comprehensive review of the effect of opt-out systems on organ donation, the University of York reviewed Abadie and Gay’s study, found it to be robust and noted it as a study with no major methodological flaw. The University of York review went on to state: “Presumed consent alone is unlikely to explain the variation in organ donation rates between different countries. A combination of legislation, availability of donors, transplantation system organisation and infrastructure, wealth and investment in healthcare, as well as underlying public attitudes to and awareness of organ donation and transplantation may all play a role, although their relative importance is unclear. The between country comparison studies overall point to presumed consent law being associated with increased organ donation rates (even when other factors are accounted for) though it cannot be inferred from this that the introduction of presumed consent legislation per se leads to an increase in donation rates. The before and after studies suggest an increase in donation rates following the introduction of presumed consent legislation, however it is not possible to rule out the influence of other factors on donation rates. 2) It is important to note that the survey evidence is incomplete and the variation in attitudes between surveys may reflect differences in methods and the phrasing of questions. Some surveys suggest a lack of public support for presumed consent, both in the UK and in other countries. However, more recent UK surveys provide evidence of support for presumed consent.”</p>	<p>NA</p>

			<p>The paper then continues: “Overall then, it is clear that on the basis of available evidence, changing to an opt-out system of organ donation in Wales is much more likely than not to result in an increase in donation and transplantation rates. It is also the case that we cannot be definite about the magnitude of any increase that is likely to occur, partly because of the changes currently being introduced to the current opt-in system (the ‘do nothing’ option), and because the purpose of the RIA is to establish the impact of the proposed legislation against the ‘do nothing’ option.”</p>	
Organ donation and transplantation activity report 2012-2013	May 2013	Review of key stats and data around organ transplantation rates, transplant waiting lists and survival rates following transplantation	<ul style="list-style-type: none"> • Organ donation has risen for the past 8 years – donors are becoming older, more obese and less likely to have suffered a trauma-related death. • 31% of the population is on the ODR but 35% of deceased organ donors were on the ODR. • 58% of new registrations in the past year come from the DVLA. • 88% of those on the register would donate all their organs. Of the 12% who would not, 88% would not donate their corneas. • The highest age proportion on the ODR is 21-30. • 67.8% of deaths audited for the Potential Donor Audit were approached over the issue of organ donation. • Consent rates for DBD and DCD combined is 57.4% (Its 67.6% for DBD and 51.3% for DCD). • (Barring the Channel Islands) Consent rates for DBD are lowest in London at 58.4% vs 67.6% for the whole of the UK. • Consent rates for DCD are lowest in Wales at 40.8% vs 51.3% for the whole of the UK. • Overall consent rates for BAMEs are lowest in London at 34.3%. It is 62.5% for white donors in London. • Consent rates when a SNOD is involved are 65.8%. It is 36.7% when they are not involved. 	Stats are sourced from various places: Potential Donor Audit (which audits approx. 29,000 deaths that take place in ICUs and emergency departments) ODR

<p>Dying Discussing and planning for end of life, British Social Attitudes 30, Janet Shucksmith, Sarit Carlebach and Vicki Whittaker</p>	<p>May 2013</p>	<p>Paper and research looking into British public’s attitude to death.</p>	<p>Although 70% of the public say they are comfortable talking about death, 73% claim to be confident of their financial plans and 79% confident about planning support and care; this is not always translated into ACTUAL planning and discussions.</p> <p>43% have not discussed their death wishes and this is 23% of those aged 75+</p> <p>In the study people are asked: Where they would prefer to die – 67% say at home; People feel their key priority if they were to die at home would be to die pain free.</p> <p>In this study the main reason people said they hadn’t discussed end of life wishes was because it felt a long way off. However, those 75+ were more likely to say that it was because people did not want to talk to them about death.</p> <p>Just over a third of all people have made a will.</p> <p>The study has a section on organ donors and organ donor cards and the numbers are in line with ODR figures.</p>	<p>The NatCen Omnibus employs a stratified random probability sample drawn from the Postcode Address File (PAF). All sectors in mainland Great Britain (England, Wales and Scotland), excluding the area of Scotland north of the Caledonian Canal, were covered. A total of 3,060 addresses were issued addresses, each selected with equal probability. A single adult (defined as anyone aged 16 or over) was then selected at random out of all adults residing at that address to take part in the survey. [For comparability with British Social Attitudes data, anyone under 18 has been excluded from the analysis for this chapter.] Interviews were carried out by NatCen interviewers using computer assisted personal interviewing. Fieldwork ran from 23rd July to 20th September 2009. The overall response rate was 49%, giving 1,375 interviews. The weighting for the Omnibus survey consisted of two components: selection weights to correct for individuals’ differing probabilities of selection, and calibration weighting to adjust the weighted achieved sample to match population estimates. The calibration weights were then scaled to give the final weight.</p>
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Potential Donor Audit NHSBT 2012-2013	April 2013	What factors affect whether a person becomes a deceased donor or doesn't.	<p>This report covers the stats that are uncovered in the Organ Donation and Transplantation Activity report regarding how the number of potential donors decreases at each stage of the process. The paper then goes into looking at the reasons families refused to consent to a donation.</p> <ul style="list-style-type: none"> • In DBD, the leading reasons are: <ul style="list-style-type: none"> ➤ Patient had stated in the past that they did not wish to be a donor – 21.1% ➤ Family were not sure whether patient would have agreed to the donation – 12.9% ➤ Family did not want surgery to take place on the body – 11.8% • In DCD, the leading reasons are: <ul style="list-style-type: none"> ➤ Patient had stated in the past that they did not wish to be a donor – 17.5% ➤ Family were not sure whether patient would have agreed to the donation – 15.8% ➤ Family felt the length of time for the donation process was too long – 14.5% • When potential donors were known to have expressed a wish to donate (i.e. on ODR, had discussed it) the consent rate for DBD was 96% and for DCD was 55%. When this was not in place, consent rate was 55% for DBD and 40% for DCD. The rates for all types of potential donors were 88% vs 46%. • The difference in in consent rates across different ages for DCD is statistically significant. The lowest consent rate (somewhat understandably) was for 0-17 year olds at approx. 28% whilst the DBD consent rate for this age group was 58%. • The difference between whites and BAMEs in terms of consent rates is statistically significant. The overall consent rate for whites is 61.1% while the overall consent rate for ethnic minorities 33%. 	Data derived from the Potential Donor Audit form
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<p>A Randomised Controlled Trial to Test if a Simple Anticipated Regret Manipulation Leads to a Significant Increase in Organ Donor Registrations</p> <p>Prof R O’Carroll, Prof. E. Ferguson, Prof. P.C. Hayes, & Dr L. Shepherd</p>	<p>April 2013</p>	<p>This study tested whether simply asking people to rate the extent to which they anticipated feeling regret for not registering as a posthumous organ donor increases NHS Blood and Transplant (NHSBT) verified organ donor registration.</p> <p>The research team initially hypothesised that simply asking people to think about and rate the extent to which they anticipated regret for not registering as an organ donor increases organ donor registration.</p>	<p>Participants received questionnaires as detailed in the right hand methodology column.</p> <p>Contrary to pilot studies (O’Carroll et al., 2011a 2011b), intention to treat analysis (n = 9,208) revealed that people in the NQC condition were more likely to register as an organ donor than participants in the QC, TPB, and AR arms. Similar results were found when the analysis was restricted to those who returned the questionnaires. Asking participants about potential emotional barriers to organ registration may have cancelled out any positive effects of the AR condition.</p> <p>For those that completed the questionnaire, the percentage of people who registered as an organ donor registration after receiving the questionnaire rates were greater in the NQC arm (43.33%) than the QC (33.87%), TPB (37.33%) and AR arms (36.08%). These results reflect the fact that completing the questionnaire reduced the likelihood of people registering as an organ donor relative to the NQC arm. However, the measured anticipated regret variable did positively predict organ donor registration intentions and behaviour.</p> <p>This simple anticipated regret intervention did not increase organ donor registration. This may have been because the participants in the QC, TPB and AR (but not the NQC) arms completed a series of questions assessing their negative feelings towards organ donation. Although these items needed to be included in this research, they may have reduced the effectiveness of the intervention.</p>	<p>A randomised controlled trial</p> <p>A total of 14,509 questionnaires were posted to members of the Scottish general public.</p> <p>The questionnaire that people received varied between conditions.</p> <p>In the no-questionnaire control (NQC) arm, participants answered some demographic questions.</p> <p>In the questionnaire control (QC) arm, people rated these questions plus their feelings about organ donation and intention to register as a donor.</p> <p>In the theory of planned behaviour (TPB) arm, participants completed the same questions as the QC arm plus items assessing their attitude towards organ donation, how friends and family viewed this action, and how much control they believed that they had over registering as a donor.</p> <p>Finally, in the anticipated regret (AR) arm, participants answered the same questions as the TPB arm plus two items measuring how much regret they would feel if they did not register as a donor.</p> <p>Six months later, asked NHS Blood and Transplant to search the organ donor register to see how many of our participants registered after receiving the survey.</p>
<p>ICM Research, Organ Donation</p>	<p>March 2013</p>	<p>Survey carried out for The Royal College of Surgeons about people’s views on Organ Donation and the ODR</p>	<p>The key questions are around whether a person would accept an organ.</p> <ul style="list-style-type: none"> • 60% definitely would while 27% probably would, 3% definitely wouldn’t. • 56% felt that TV campaigns were the best way to be kept informed about organ donation while 49% went for GPs raising the issue with their patients. • 61% said they hadn’t seen any information or campaigns about the ODR in the past 6 months. 	<p>Not fully outlined, but appears to be an online panel survey of the general public with 2024 respondents.</p>

Organ Donation Campaign Evaluation Scotland TNS	Feb 2013	Evaluation of Wee chat campaign that ran in 2012	<p>53% claimed to have seen advertising about organ donation.</p> <p>Older people and higher socio-economic groups had higher levels of awareness.</p> <p>Approx. 54% recognised the campaign mid campaign while 60% recognised it post campaign.</p> <p>Interestingly, there was more recognition with lower socio-economic groups post wave.</p> <p>Registration messages were understood by 43% while the discuss message was understood by 39%.</p> <p>TNS Adeval measure was also performed. Amongst those who had or hadn't seen the ad when it aired, 59% were motivated by it – this was 69% amongst those who had seen the ads broadcast.</p> <p>59% of everyone claimed the ad encouraged you to think more about discussing organ donation with loved ones. 28% had claimed to have taken action as a result of seeing the campaign mid-campaign while 25% had claimed to have done so post-campaign. 15% mid-campaign and 17% post-campaign had claimed to have talked about it with someone. 6% mid-campaign and 3% post campaign had claimed to have signed up to the ODR. As a separate measure people were asked if they had discussed organ donation (regardless of any campaigns) – in the benchmark 40% claimed to have done so, mid-campaign 47% claimed to have done so and post-campaign 54% claimed to have done so.</p> <p>The increase in organ donation discussion seems to come from: Females 25-34 65+ ABs (although some increase in the other socio-economic groups)</p> <p>A series of attitudinal statements were also tested:</p> <ul style="list-style-type: none"> • <i>I believe we should discuss our wishes about organ donation</i> (41% strongly agree benchmark, 43% post wave – most common response) • <i>It is unacceptable not to donate your organs</i> (27% slightly agree benchmark, 26% post – most common response, some movement to more strong agreeing) • <i>“It is not acceptable for your family to overturn your wishes to become an organ donor in the event of anything happening to you”</i> (37% benchmark strongly agree, 33% post) • <i>“Everyone should be presumed to be willing to be an organ donor unless they register a wish otherwise”</i> (26% strongly agree) • <i>How likely are you to put your name on the ODR?</i> (Very likely 9% benchmark, 11% post. Biggest answer might or might not 37% both waves) <p>Nearly all demographics saw a slight upswing in being likely to sign the ODR bar those aged 35-44 whose numbers slightly went down.</p> <p>Strongest performance of campaign amongst those currently registered; whilst this will not therefore grow registration levels, ensuring wishes are carried out is an equally important outcome.</p> <p>More subtle message of encouraging people to discuss their wishes may be getting lost amongst more obvious, and assumed, message of asking people to register. ‘Discussion’ aspect also less well picked up by males to some extent.</p> <p>There is a positive environment for the campaign given general absence of noise, therefore important to continue: significant levels of indecision towards organ donation also highlight the potential opportunities. To extend reach may need to broaden media mix beyond TV, especially to target younger age groups.</p>	<p>TNS BMRB in-home face-to-face Omnibus (SOS) Interviews with adults 16+ across Scotland, geographically representative of Scotland’s population. Weighted findings from three waves of tracking have been used in this evaluation: HTS Benchmark: A total sample of 1,175, comprising 1,008 adults aged 16+ interviewed between 26th Sep – 4th Oct 2012 and 167 boost interviews among 25-64 C2DEs interviewed between 26th Sep – 16th Oct 2012. Mid wave: 982 adults interviewed between 21st – 29th Nov 2012. Post wave: 1,015 adults interviewed between 23rd – 31st Jan 2013.</p> <p>All interviewing was carried out face-to-face in-home using multi-media CAPI. Interviewing was conducted in sampling points across 70 (Benchmark), 54 (Mid) and 55 (Post) constituencies selected to represent Scotland geographically and demographically (68 constituencies were covered on the Early Dec SOS). Quotas were set according to gender, working status within gender and within females, presence of children in household.</p> <p>The majority of interviewing was carried out at weekends or on weekday evenings after 5pm.</p>
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Draft Engagement Strategy BAME & Faith Groups Human Transplantation (Wales) Bill	Jan 2013	<p>This document sets out:</p> <ul style="list-style-type: none"> An appraisal of the position of the sector with regard to organ donation and the new legislation; (see sections 'Summary of Key Findings', 'Appendix A' and 'Appendix B') Recommendations as to the most appropriate means to engage with the sector (see section 'Engagement/ informing events and activities'). 	<p>Stage one of the document outlines each faith's view on organ donation and their views on the Welsh bill. The document then outlines three strategies for engaging key faith and BAME groups such as visiting Mosques and Polish Churches.</p>	NA
Remember a Charity Impact Report	2013	<p>This report looks at the work of the Remember A Charity organisation.</p>	<p>Key impacts that the report outlines are:</p> <ul style="list-style-type: none"> The percentage of solicitors and Will-writers who 'never' prompt about charity has halved in the past two years. The percentage of Wills that go to probate with a charitable gift has increased from 12.2% in 2007 to 14.4% in 2012. A national benchmark survey also shows that there has been a significant shift in awareness about legacy giving in the past two years, reaching its highest level to date. In the past five years alone, the public has viewed more than a million pages on Remember A Charity's Website. Remember A Charity led a six-month trial with the Cabinet Office Behavioural Insights Team and Co-operative Legal Services, which showed that when solicitors or Will-writers simply mentioned to people that leaving a gift to charity was an option, the percentage of people who did so rose from just 5% to 10%. Legacy giving rose again, to 15%, when people were asked if there were any charities that they were passionate about; average donations also increased by 50%. 	<p>Various bespoke studies and organisations' own tracking of inputs and outputs</p>
Opt-out systems of organ donation: International review of evidence, Melissa Palmer, Welsh Government Social Research	Dec 2012	<p>A review of intentional opt-out systems undertaken by the Welsh Government</p>	<p>This paper states that:</p> <ul style="list-style-type: none"> International evidence suggests that an association exists between presumed consent legislation and increased organ donation rates Recent surveys indicate that there is significant support for the introduction of an opt-out system for organ donation in Wales Experimental literature provides evidence for a mechanism through which presumed consent might increase organ donation, through the influence of the default position. <p>The paper then suggests that "In combination, these three strands of evidence provide a convincing basis for the introduction of an opt-out system in Wales. However, there can be no guarantees that this legislative change will result in increased organ donation rates."</p> <p>The paper further explains this point:</p> <ul style="list-style-type: none"> Given the complexity of decision-making surrounding organ donation consent, it is unlikely that a single piece of legislation alone will be responsible for an increase in organ donation rates. An opt-out system changes the default position to be in line with the (reported) wishes of the majority and this may overcome the inertia that limits the explicit registration to opt-in, while providing a new opportunity for those who definitely do not wish to donate to record their wishes by opting out. Where legislation is changed, communications campaigns and factors related to practical implementation at the ground level will likely be important factors in the legislation's success..... 	<p>Full literature review</p>

Public attitudes to organ donation: Baseline survey 2012 (Wales)	2012	<p>Research into:</p> <ul style="list-style-type: none"> Public attitudes towards the implementation of the new organ donation system in Wales (opt-out) Public awareness of the current and prospective organ donation systems Families and knowing/overturning organ donation wishes of a loved one <p>The research was undertaken with the view to inform how communications are targeted among different groups of the population.</p>	<p>The paper provides factual representation of the results – it does not examine causal links or infer recommendations. Some relevant findings were:</p> <ul style="list-style-type: none"> The proportion of respondents who had discussed their wishes regarding organ donation with a family member tended to be lower among 16-34 year olds; men; respondents from lower social grades. A third of Welsh people agreed ‘organ donation is a gift’. 62% of respondents felt their family would know their wishes in the event of their death. 73% supported that ‘the deceased person's wishes about donating their organs or not should be respected no matter what the family thinks’. 	<p>1,006 respondents were interviewed as part of the June 2012 wave of the Wales Omnibus Survey.</p>
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NHS Organ Donor Register Research Scotland NHS	Aug 2012	<p>Following organ donor registration reaching 40% in Scotland, research was commissioned to try and increase register numbers by:</p> <ul style="list-style-type: none"> • Investigating level of support for organ donation • Comparing claimed registrations with actual registrations • Investigating reasons for not registering 	<p>Around three quarters of the Scottish pop support organ donation.</p> <p>29% in the study claimed to be on the ODR.</p> <p>Middle age groups and the higher socioeconomic classes make up most of those registered.</p> <p>28% claimed to carry a card.</p> <p>Around three quarters of those registered said that they would confirm registration if asked to do so – although some said this might make them lose confidence in the ODR.</p> <p>Apathetic reasons given for not joining ODR, although for younger people it's time and for older people it's because they think they are too old.</p> <p>AB non-registrants are more likely to say they haven't got around to it while DE non-registrants thought they were too unhealthy. However, not being aware of the register or having enough information on it comes out when people are prompted.</p> <p>A quarter of those not on the register said they are likely to join in the near future.</p> <p>For those not registered, online is the preferred way of joining up.</p> <p>TNS's comments on the results are interesting as they highlight how the ODR needs to make a bigger thing of people signing up so they can remember they are on it.</p> <p>Registration levels are lower than anticipated with only 29% claiming to be registered: even assuming 'don't knows' are on the register, this is much lower than the figure of 42% - as indicated by the actual names on the register.</p> <ul style="list-style-type: none"> • The hypothesis that there is a reasonable pool of people believing they are on when they are not is not supported, rather evidence suggests people are more likely to be on register but unaware of it. • Confusion/lack of recall perhaps generated by simplicity and process of OD registration – particularly when combined with some other registration – especially if it's not acknowledged? • Lack of practical knowledge is evident though, especially in relation to registration process, whether there are age/health criteria and whether particular organs can be specified for donation. • Emotional barriers (thinking about death/tempting fate) secondary to general sense of personal apathy/lack of importance/connection to the register. • Assuming database is accurate and up-to-date, need to ensure that those on the OD register know it! Potential benefits of positive word of mouth are lost if people can't act as advocates. • Once registered there should be a mechanism for reminding people that they have signed up. • Lack of appetite to register confirms need for high profile multimedia campaign: TV/radio required to raise profile, promote broad practical messages (no exclusions, easy to sign-up, choose which organs) reinforce the benefits and, most importantly, to support tactical advertising. • Direct response mechanisms will be more effective when supported by the TV campaign; to include, for example, click through online advertising to reach core ABC1, middle age range. • Role also for further support/promotion amongst stakeholders – GP surgeries, family centres, libraries, etc. – especially for those who prefer paper-based registration. • Field marketing also effective given its ability to achieve immediate results through face-to-face contact. 	<ul style="list-style-type: none"> • Interviews administered using in-home multimedia CAPI (Computer Assisted Personal Interviewing), with quota sampling applied: • Data weighted to be representative of Scottish adult population according to gender, age, working status and SEG • Weights derived from BARB (Broadcasters' Audience Research Board) Establishment Survey 2 years ending December 2008 and the 2001 Census • 1,006 interviews conducted between 25 July – 1 August 2012 in 69 constituencies across Scotland • The organ donation section asked as self-completion – as a sensitive subject and to minimise socially desirable responding
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Scottish Organ Donor Register (SODR): Historic Benchmarking & Trend Review	Aug 2012		<ul style="list-style-type: none"> • Year-on-year registrations up 20% in 2011, and on course to hit the same number 2012 • Women are leading the growth in registration • SODR is getting older, both in terms of: <ul style="list-style-type: none"> ➢ Who's signing up now ➢ The current age of the register ➢ Acorn shows that people registering on the SODR are largely reflective of the Scottish population ➢ Where they live ➢ Social class • Source of recruitment has changed markedly over the last two years <ul style="list-style-type: none"> ➢ DVLA and FHSA (huge lift in 2011) still dominate but they are declining as a proportion ➢ "Other" grew by 350% between 2009 and 2010, and has continued to grow since – DM/Field is the major contributor ➢ Web peaked in 2010 and has fallen away since – why? ➢ Recruiting the older donor (50+) now largely coming through Other, replacing DVLA ➢ Proportion of those ticking all organs donate box is continuing to decline ➢ Younger women continue the theme of not wanting to donate corneas • UK year-on-year registrations down 4% in 2011, and on course to decline further in 2012 <ul style="list-style-type: none"> ➢ Scotland bucks national trend... • Scotland is moving to be more in line with the UK in terms of the older age profile of registrations • Scotland (still) continues to be relatively weak in recruiting the youngest and the oldest groups of the population, and men generally • Scottish sources are different: <ul style="list-style-type: none"> ➢ Less reliance on DVLA ➢ More reliance on FHSA ➢ "Other" category now 2.5 times more likely to be an SODR compared to UK • Encouraging trends in growing registration volume, particularly amongst the older generation <ul style="list-style-type: none"> ➢ Scotland is bucking the trend in terms of recruitment ➢ Proactive recruitment is helping support this growth and appears to be necessary for the recruitment of older donors (they need a push) • The major concerns going forward: <ul style="list-style-type: none"> ➢ Youngest and oldest age groups and men not as engaged and it is peculiar to Scotland as rest of UK doesn't carry to same marked trend ➢ Willingness to donate all organs is falling – corneas is a problem for the young ➢ Areas for further research ➢ Recruitment – young, very old and men generally – what is it about Scotland and the ODR? ➢ Source: Other – can we categorise so that direct marketing efforts are isolated ➢ Source: FHSA – why the growth, what's happening? ➢ Source: Website – why the decline – is this a result of FHSA upturn or something to do with the website itself? • The proactive, targeted approach to recruitment in recent years is paying dividends • Improvements in recruitment levels can still be made, however, particularly for the U20s and over-50s • U20s should be considered less of a problem long-term as the trend shows they register as they get older <ul style="list-style-type: none"> ➢ Education therefore a primary focus – family and school ➢ An area to continue focus should be the over 50's generally, and older men specifically 	Not outlined – presume analysis of existing Scottish ODR data
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			<ul style="list-style-type: none"> The evidence supports that this age group continues to need a push as other recruitment sources generally ‘miss’ them. 	
Scottish Organ Donor Register DM Campaign Evaluation	May 2012	<p>Evaluation of DM campaign targeting the older generation Selections: Main: 40 years plus and propensity to register (model – built on individual response, expressed at household level) MGM+: registered OD from previous campaigns Creative execution Letter: best performer from previous campaign, with MGM element Postcard follow-up MGM+ letter</p>	<ul style="list-style-type: none"> Mailing universe = 1,100,000 households, 1,583,000 individuals 5 waves of activity 60,000 mailings per month main letter Reminder mailing to follow after 4 weeks (dropped for last two waves) 5,500 mailings for MGM plus <p>Campaign target 30,000 responders, 25,621 so far...still getting 100 a week on average 9.7% response rate in Nov 2011 for mailing excluding MGM+ 14.2% for MGM+ in Dec 2011 Total CPA was £10.55 Did well with older age groups 2010 campaign Response: 10.9% 2011/2012 campaign Response: 8.0%* * **As at 4th May</p>	NA
Organizations as Communities: Creating Worksite Campaigns to Promote Organ Donation, Susan E. Morgan Purdue University USA	Feb 2012	This paper is about university and workplace-based organ donation campaigns and their results	<p>Initiatives looked at in this report include:</p> <ul style="list-style-type: none"> UPS initiative 1999-2000: This looked at the effects of mass media campaigns and personal interventions on organ donor registration. The results broadly proved that these interventions make a positive difference but there is not enough data to explain what interventions work best. The university worksite organ donation campaign: The campaign heavily utilised internal media including campus papers and faculty/staff newsletters in addition to more traditional outlets such as billboards and radio. In one of the quasi-experimental conditions, only media messages (including those that featured the stories of members of the university community) were used to promote organ donation. In mass media-plus-interpersonal condition, the media campaign was supported by ten on-site visits by OPO staff and volunteers over the course of an academic year. A random stratified mail survey demonstrated that compared to the control condition, there was a statistically significant advantage to adding on-site visits on whether respondents reported signing a donor card or talked to family about organ donation. However, the media-only campaign did not produce results that were statistically different from the control condition. The project organisers argue that the outreach component offers community members the opportunity to “put a human face” on the issue of organ donation because many volunteers are transplant recipients or donor family members. Additionally, the site visits provide an opportunity to ask questions about organ donation that may linger even after seeing ads or billboards promoting organ donation. The New Jersey Workplace Partnership for Life. This project reached over 30,000 employees in 45 companies in industries including health care, pharmaceuticals, manufacturing, law, education, and municipalities. Companies were divided into three quasi-experimental conditions that replicated those of the University Worksite Organ Donation Project (mass media campaigns contrasted against campaigns that also included on-site visits by staff and volunteers). In addition to expanding the number and diversity in the type of companies reached, campaigns were reduced to a 10-week time period. In addition to “myth buster” messages designed to educate employees about the most common misconceptions about organ donation, companies in the mass media condition publicised the stories of co-workers who had been touched by organ donation. About half of all companies had employees willing to share their 	Literature and study review

			<p>stories; in the event that an employee story was not available, stories about people in the same industry or the same town were used instead to maximise a sense of affiliation. All media messages were disseminated through internal (not external or paid) media, including email, cafeteria table tents, newsletters, posters, pay check stuffers, and LCD boards.</p> <p>Depending on the size of the company, which ranged from 100 employees to nearly 4,000 employees, on-site visits to companies in the high-intensity campaign group were conducted 3-4 times over the course of the 10-week campaign. Tables were set up in high-traffic locations, including lobbies and cafeterias and were typically staffed by two project team members and a volunteer from the organ procurement organization, usually a transplant recipient. A panel from the state's donor family memorial quilt was on display to further promote a sense of personal connection with the issue. Small giveaways such as pens, magnets, and sticky note pads helped to attract attention to the table, where staff members then used a set script to engage employees in a discussion about any questions about donation or the state's organ donor registry.</p> <p>Results from pretest/post-test surveys of a random sample of employees confirm previous findings that campaigns which include on-site visits are more successful than those that use only internal media to disseminate information about organ donation. Mass media campaigns, which utilised only internal forms of media (newsletters, posters on bulletin boards, paycheck stuffers etc.) increased the rate of donation among non-donors by an average of 13.6%.</p>	
KPMG report	August 2011	<p>The Organ Donor Register (ODR) currently exists in the context of policy uncertainty as to the preferred future strategic direction for organ donation in the UK.</p> <p>NHSBT management have undertaken a review of attitudes to the ODR, covering both the general public and health professionals.</p> <p>The requested scope to this study did not include an assessment of the whether or not an ODR continues to be required.</p> <p>This report focuses on delivering improved performance within the current policy landscape; it has been assumed that an ODR continues to be required.</p> <p>Strategic questions that were asked include: 1) What delivery mechanism is most appropriate for the operation of the ODR? –Should delivery channels be rationalised? 2) Should access to the ODR be widened and the system made more interactive? –For the public? For healthcare professionals? 3) What impact does the strategic vision have on the IT architecture requirements for the ODR? 4) What ownership option is best suited to deliver the ODR?</p>	<p>NHSBT currently receives donor registrations through a number of channels:</p> <ul style="list-style-type: none"> • 10 partner feeds (e.g. DVLA, Connecting for Health, Boots) • Web registrations • Postal registrations (processed by ADS) • The national call centre • The variation in data format and standards across the multiplicity of current channels enhances the risk of error and increases the cost of operating the ODR as elements of manual processing are required, particularly for postal registrations. • In addition, the volume of registrations received from each channel is not equal. The cost to serve some of these channels may outweigh the comparative benefit received. A transition to focus on web registrations may be beneficial. <p>The report suggests that registration channels should be rationalised and standardised, focusing on those that produce significant levels of registrants (for instance, those greater than 10k registrations per annum) and peripheral partner feeds redirected via NHSBT website registration.</p> <ul style="list-style-type: none"> • Additional focus should be placed on developing registrations via the NHSBT website as the main alternative channel. • Email addresses should be collected for correspondence purposes from all sources, where available from the registrant. <p>For the public</p> <ul style="list-style-type: none"> • It has been argued that increased ODR interactivity may encourage greater public engagement and increase the reliability of data. • However, particular outcomes from the public engagement study suggest that whilst there is some interest in being able to access registration records online, this is not a key requirement. There is also some concern over the security of personal information online. <p>For healthcare professionals</p> <ul style="list-style-type: none"> • NHSBT currently plans to give Specialist Nurses for Organ Donation (SNODs) direct access to the ODR from September 2011. • Feedback from the engagement with Clinical Leads for Organ Donation (CLODs) suggests that they would prefer not to have access to the ODR, because of the perception that it might influence their medical judgement. This view is also supported by the general public. 	NA

			<p>Given the lack of strong demand for interactive access to the ODR from the public, the development of an online platform does not appear to be an immediate requirement. However, if registrants were given access to, and responsibility for, their own data, data held on the ODR would be less of a risk for NHSBT, and the required resource to maintain the system and communicate with registrants would be reduced.</p> <p>Implementing self-service access will incur costs and present challenges around authentication and personal data security.</p> <ul style="list-style-type: none"> • An ability to facilitate this self-service requirement in the future, should be a consideration for any IT system design. • Wider access to the ODR for other healthcare professionals (over and above what is currently planned) is not required as it increases the risk and perception of inappropriate use of data. • Any policy decision to move to an alternative system of consent in Wales would drive the need for a fundamental redesign of the ODR system. This could create an opportunity to consider additional functionality, such as online self-service. <p>In view of the small scale of the ODR (c£4.5m for total operations) and the lack of commercial upside potential, future ownership and delivery options that involve the transfer of operations to the private or third sectors seem inappropriate. This also is consistent with the public consultation, which found that the public is against private sector solutions.</p> <p>A series of key IT considerations are also outlined.</p>	
<p>KPMG PowerPoint Organ Donor Register Public Engagement Study for KPMG and NHSBT, BDRC Continental</p>	<p>August 2011</p>	<p>This report looks specifically at the people's views on the ODR sign up process.</p>	<p>Length of form largely has no impact on likelihood to register, with a slight preference for a shorter questionnaire, however, much longer is likely to alienate.</p> <p>Despite a marginal preference for a shorter questionnaire, there is opportunity to ask a few further questions, with stronger support for these amongst those who are likely to register in the future.</p> <p>Consent can be raised at registration, but ideally donors should discuss this with their family beforehand.</p> <p>Opt-in future contact would be useful to confirm registration details, and allow periodic checking of details every few years etc. (which should help avoid duplicate registrations).</p> <p>Scotland more put off by the short form and single question approach.</p> <p>Age: some preference amongst 25 to 34 year olds for more detailed questions.</p>	<p>Qualitative research with the public: 4 groups conducted by added insight, to gain initial understanding of public attitudes and perceptions, and help shape quantitative stage.</p> <p>Quantitative research with the public: 1,103 interviews conducted by bdrc continental, face to face (target of 1,000) across the UK, with adults aged 16+ and excluding those not against organ donation in principle. 10 minute interview.</p> <p>Qualitative research with Clinical Leads and Specialist Nurses Organ Donation: Scoping sessions with NHSBT followed by 2 discussions (1 with clinical leads and 1 with specialist nurses). Interviews in Wales, Scotland and Northern Ireland were boosted to provide robust numbers in each country. These proportions were correctively weighted to the UK geographic profile at reporting stages. A representative sample of UK residents was interviewed with quotas applied by gender age and social class.</p>

Organ Donor Register: When it is better to receive than to give, IPA paper, Ila De Mello Kamath & Bridget Angear (AMV BBDO)	2011	Evaluation of the Prove It campaign	<p>The objective of the campaign was to increase the number of registrations on the Organ Donor Register (ODR) from 16 million to 25 million in three years, specifically generating 37,600 registrations in the first five weeks. Insight reframed the problem: organ donation was not about altruistic giving, but about reciprocation, people will give because they want to receive. The campaign put people in the mind-set of the recipient, and in doing so was able to generate sufficient empathy as well as self-interest to encourage them to register.</p> <p>In the first five weeks, the campaign generated 128,218 completed registrations, four times more registrations than the same period the previous year. The campaign exceeded the previous year's registrations by 400%; it is likely to have helped save five lives, which at a financial cost of a life saved in a society of nearly £1m, gave a ROMI of 4:1. In the first five weeks, the campaign generated 128,218 completed registrations, four times more registrations than the same period the previous year.</p>	NA
Public awareness of and support for organ donation in the UK: guiding communication, Synovate	2009	<p>NHS Blood and Transplant (NHSBT) commissioned this programme of market research in order to inform a UK-wide multimedia campaign to run in 2009/10.</p> <p>While 91% of people in the UK are not opposed to organ donation in principle, only 26% are currently registered on the NHS Organ Donor Register (ODR). This research seeks to investigate the real (as opposed to stated) reasons, rational and emotional, as to why the majority of the UK population has not currently signed up to give consent for their organs to be donated after their death.</p>	<p>The report posits that the key communications challenge for NHSBT is prompting people to be aware of and care sufficiently about the issues of organ donation, such that people will be motivated to register on the ODR and make their wishes known to those closest to them.</p> <p>The research demonstrates that people are most likely to respond to a communications campaign incorporating a personal, emotional tone and content.</p> <p>The communications campaign should focus initially on the sections of the population not registered on the ODR who are more receptive to organ donation generally.</p> <p>The campaign must be explicit that registering on the ODR is the desired action, and frequent reminders and opportunities to register must be presented.</p> <p>87% say they would honour their family's organ donation wishes if they are made known on the ODR. However, only 44% say they would allow a family member's organs to be donated if their wishes were not registered on the ODR.</p> <p>The importance of acting now must be stressed.</p> <p>Other sections of the population not currently on the ODR are less likely or ready to register. Communications will be less able to persuade and prompt them to do so, compared with those ready to act and who need to involve their family.</p> <p>Synovate findings suggest that any NHSBT organ donation campaign needs to meet a number of requirements to be successful.</p> <ul style="list-style-type: none"> • Target two specific segments of the unregistered population who are closest to registering straight away, but who need a prompt to encourage them to do so: <ul style="list-style-type: none"> ○ people who say they are ready to register now; and ○ people who say they need to discuss the issue with their family before registering. • Engage them in a highly personal and emotional way. A purely rational approach appears less likely to motivate people to make the effort to register on the ODR. • Convey a sense of immediacy, i.e. that people need to register now. • Motivate people to care sufficiently to make the effort to go online and register on the ODR. • Prompt people frequently to go and register to make sure they make the effort to do so(e.g. through a heavy weight of advertising). <p>There are sufficient numbers of people within the two target segments for NHSBT to achieve the level of registrations required.</p> <p>It would take significantly higher levels of investment to motivate other segments of the unregistered population to go online and register now. Consequently, they should be considered secondary, longer term targets. However, a personal and emotive campaign is also likely to encourage other population segments to be more positively predisposed to registering on the ODR.</p>	<p>14 focus group discussions, predominantly among people who were not currently registered on the organ donor register (ODR), but who were not opposed to registering.</p> <p>A face-to-face survey with a random sample of 1,540 members of the general public and 1,463 people from black and minority ethnic (BAME) communities.</p> <p>All survey respondents were not opposed to the principle of organ donation, but were not currently registered on the ODR and did not carry a donor card.</p>

The Intersection of Conversation, Cognitions, and Campaigns: The Social Representation of Organ Donation, Susan E. Morgan <i>Communication Theory</i>	2009	<p>A social representation is “a system of values, ideas, and practices with a twofold function: first, to establish an order which will enable individuals to orient themselves in their material and social world and to master it, and secondly to enable communication to take place among the members of a community by providing them with a code for social exchange and a code for naming and classifying unambiguously the various aspects of their world and their individual and group history” (Moscovici, 1973, p. xiii). Perhaps more simply put, “social representations are more or less popular cognitive representations of relevant [novel] phenomena” (Sommer, 1998, p.186).</p> <p>This paper suggests that SRT could help researchers and practitioners understand the complex interplay of factors within a population(s) that contribute to reluctance to donate organs after death.</p> <p>It is argued that public communication campaigns should include strategies to provoke interpersonal communication about the topic as a means of creating social representations that promote behaviours that support public health.</p> <p>This paper first reviews SRT, then reveals how SRT has resulted in a richer understanding of the emergence of individual and social behaviours regarding organ donation willingness through multiple, programmatic studies in both Australia and the United States.</p> <p>Although this paper has been written from a US perspective, much can still be gleaned and applied to the UK.</p>	<p>This paper points out how a number of scientific and medical innovations, including stem cell research, the use of biotechnology in food production, and organ donation, have all been framed using “Frankenstein” imagery. The media has also posited that transplantation can fundamentally transform a human being into a state of hybridity.</p> <p>Organ donors are depicted as “good people” in entertainment media, participants rationalized their decisions to group images of “donors” or “non-donors” based on whether they interpreted the photographs as representing educated, generous, or religious people or, alternately, as conservative or uncaring.</p> <p>The organ allocation system is often depicted as unfair (favouring the rich, powerful, and well connected) and the medical system as corrupt, including vulture-like doctors; non-living donors themselves were shown as little more than sources of spare parts for people in need of a transplant.</p> <p>On one hand, donation is seen as the ultimate altruistic gesture, a sacrifice of one’s body (which to some poses certain existential risks) so that another person can live. There appears to be social consensus that those who donate or who sign a donor card are good people.</p> <p>On the other hand, organ donation is seen as frightening, a process where an unsuspecting donor could easily be the victim of a villainous medical system that dissects and disassembles the still living to gain power and profit. SRT allows for and even expects these apparent contradictions.</p> <p>The framing of an issue in the media does not merely help shape cognitions but influences the way information is communicated between individuals and within groups.</p> <p>The paper suggests that many researchers have been overlooking a vital form of audience segmentation: social and thought communities. The concept of thought communities may help explain why campaigns targeting university communities, workplaces, and medical personnel have shown more success than most other campaigns (The Institute for Campaign Research and Evaluation, 2005). Individuals within these communities are in greater social and physical proximity to one another than members of the general public. The paper then goes on to detail some campaigns that have taken place at US universities and workplaces.</p> <p>However, the paper does look at how these campaigns’ objective is often to prompt discussion about organ donation and how sometimes these discussions can have the effect of making people less positive about organ donation. It is also pointed out that people are much more likely to talk about donation if there has been a hugely negative story about donation in the press than if there has been a campaign about donor registration using statistics.</p>	<p>Analysis of existing academic literature and research</p>
Why relatives do not donate organs for transplants: ‘sacrifice’ or ‘gift of life’? Magi Sque, Tracy Long, Sheila Payne & Diana Allardyce	Sep 2007	<p>Exploration of why people may refuse donation through in depth interviews.</p>	<p>This research suggests that donation decisions depend on a number of converging factors in the particular situation of being asked to donate and not necessarily on the views of relatives about donation, or the reported wishes of the deceased in life, except if the person had stated that they did not wish to be an organ donor. Therefore, reported pro-donation views held by the family, or the deceased in life, did not guarantee donation. Protecting the dead body, which related to keeping the body whole and intact, was the most frequently-recurring theme, being reported in 15 interviews.</p> <p>Families’ wishes to “protect the dead body” may stimulate tension between the notions of donations being a ‘gift of life’ as supported by transplant policy and it being a ‘sacrifice’ of the body, which must be made if organ donation is to proceed. This could account for the decision of participants to decline donation even if their deceased relative previously held positive views about organ donation.</p> <p>Protecting the dead body Protecting the dead body was reported in 15 interviews and was the primary</p>	<p>A convenience sample of 26 family members, who declined donation of their deceased relatives’ (n= 23) organs, were recruited via three media campaigns in large conurbations and from four intensive care units in the United Kingdom. Data was collected in 2005 using interviews.</p>

			<p>reported reason for not donating. Participants raised concerns about their deceased relative being ‘cut up’. Words and phrases such as ‘They are not cutting up my dad’; ‘When something I feel is part of the body, I feel it ought to stay part of the body’; ‘I want her to go as she is in one piece’; ‘I don’t believe people should be cut open in this way’, were features of these accounts. In particular, if the deceased relative had experienced chronic illness, participants reported that they ‘Couldn’t bear the thought of her being touched again’; ‘I just couldn’t stand the thought of her being tugged around’ and ‘I couldn’t bear the thought of her being mauled around anymore’.</p> <p>Participants’ reported feelings of guilt and selfishness about not donating, and they appeared relieved to find that they were not the only ones who did not donate organs. Three believed that people who did not agree to donation were in a tiny minority. As one explained, when she saw the advertisement for the research in the newspaper it was: ‘a bit of a relief because I didn’t feel as selfish, you know’.</p> <p>The report quotes Callahan (1987), who hypothesised that “our empathic responses to the dead are in part due to our inability to identify with the dead: we are only capable of identifying with pre-mortem states. He highlights the notion of harming the dead and the sentiment that it is possible to feel sorry for dead people because we’d think of them as they were pre-mortem. The concept of ‘sacrifice’ opens up an alternative dimension for understanding the decisions of families who choose not to donate.</p>	
<p>Scottish Executive – Life after death: the difficult business of signing people up to organ Donation, IPA paper, Giles Moffatt, Dr Stephen Tagg and Gillian Govan</p>	<p>2007</p>	<p>This paper outlines the research and thinking behind the Scottish campaign “Kill Jill”. The paper details the number of registrations the campaign generated and also extrapolates what effect this might have on donations.</p>	<p>The 2005-2006 campaign initially was driven by real life stories about donation that would appear in the media. Advertising would then be placed in and around these stories which showed real people who needed a transplant and posing questions like "Kill Jill?" or "Spare Claire?". The copy went on to read, "If you register as a donor, you could save a life. If you don't, you won't".</p> <p>A similar approach was taken with Field Marketing. The budget for the campaign was £340k over two years.</p> <p>Three key insights inspired the campaign:</p> <ul style="list-style-type: none"> • Don't provoke thought about organ donation, provoke action. • Link registration with an immediate outcome – people like to know their actions have consequences. • Emphasise the ease of registration or participation. <p>The agency behind the campaign stated:</p> <p>"The other real learning for us is that this kind of recruitment campaign depends entirely on the successful use of mass media. Our results simulation demonstrates that for every 100,000 people who register, only six kidney transplants are likely to take place. The forces of probability are against us, and for this very reason there is clear justification for increased investment in large scale campaigning."</p> <p>Tied to this was the use of advertising when there was already a groundswell of awareness through PR and field marketing.</p>	
<p>BAME barriers to organ donation</p>	<p>No date</p>	<p>Literature review of existing academic and government research covering:</p> <ul style="list-style-type: none"> • Main barriers to organ donation within BAME communities • Recommendations for overcoming barriers to organ donation within BAME communities 	<p>The main obstacles to organ donation and transplantation within the BAME communities in the UK are identified as:</p> <ul style="list-style-type: none"> ➤ Low levels of registration ➤ Knowledge of organ donation and registration ➤ Faith and cultural beliefs ➤ Bodily concerns ➤ Influence of family ➤ Trust ➤ Low rates of consent <p>Recommendations for effective ways of increasing organ donor registration among minority ethnic communities are identified as:</p> <ul style="list-style-type: none"> ➤ Creating a bank of personal case studies ➤ Increasing opportunities for obtaining information and registration ➤ Designing effective registration interventions 	

Paula Aubrey Exec Summary of PhD	No Date	<p>The overall aim of this PhD was to obtain the in-depth perspectives in relation to the timing of the approach to families for organ donation consent, how it was done, by whom and how this impacted on the choices made and the ongoing experiences of the family. A key aim was to explain to what extent the various aspects of the organ donation process differed in EDs compared with ICUs for bereaved families.</p> <p>An additional aim was to gain an understanding of the path of organ donation from consent to removal of organs and how the situational and temporal context of the ED influences the experiences of the bereaved families. This study also aimed to establish what the families’ key motivational factors were in agreeing to organ donation when faced with the shocking and unexpected death of their family member.</p>	<p>There are clear differences regarding the pathway to organ donation in the ED compared with the ICU. This is mainly attributable to the significantly different circumstances that the acutely bereaved family experience in the ED in relation to the path of time and the family’s relationship with Healthcare Professionals (HPs).</p> <ul style="list-style-type: none"> • Those dying in ED may be denied from donating their organs. • The timing of the initial approach is crucially important. • Findings demonstrate that it does not matter who in terms of which HP initiates the organ donor conversation with the family in the ED, as long as the needs of the bereaved family are met. • How the donor conversation is instigated is critically important and should only ever be undertaken by an HP who has experience in caring for suddenly bereaved families and possesses excellent communication skills to make the request in a kind, caring and compassionate way. • Bereaved potential donor families benefit by being informed in advance by the ED staff about when the Donor Transplant Coordinator (DTC) is going to be introduced to them to discuss organ donation. The family needs to know this prior to the arrival of the DTC. • Contributing factors that influenced donor families in the ED to agree to donation in this study fell into six main types. Altruism was cited in previous work (Wilkinson, 2003; Titmuss, 1970) as a key driver why families agree to organ, tissue and blood donation. In contrast, this was not the main driver for the families in Aubrey’s study. Although it was mentioned as one of their reasons, for some families, it was clear that those families who had been catapulted into a “waking nightmare” in ED were not thinking of other families when they agreed to donate; but they were thinking primarily of what their relative most likely would have wanted. A significant finding from the study was that nearly all families wanted to carry out their relative’s known wish or presumed wish. • Families need to know that their relative is being cared for throughout the whole donation process. 	<p>In total, 50 ED donor families were invited to participate in the study.</p> <p>From this number, 20 families agreed, comprising 28 participants (more than one family member was involved during some interviews).</p> <p>The bereaved donor family interviews took place between 2008 and 2011, across four regions within the UK.</p> <p>All 20 qualitative interviews were face-to-face, 17 took place in the participants’ homes and three interviews took place in NHS offices at the donor families’ request. All interviews were audio-taped. NHS Ethical approval was obtained.</p>
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