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Opt out organ donation: A rapid evidence review



HEALTH AND SOCIAL CARE



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James Niven

Health and Social Care Analysis
Scottish Government

Natalie Chalmers

Scottish Government Intern from Scottish Graduate School of Social Science

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For enquiries about this publication, please contact: James Niven, Health and Social Care Analysis, Scottish Government. james.niven@gov.scot

Executive Summary

- **Currently Scotland operates an opt in system of organ and tissue donation. This review was undertaken to provide an overview of evidence regarding opt out systems of donation and to inform the development and implementation of a workable opt out system of organ and tissue donation**
- **The majority of the Scottish population is likely to support opt out legislation for organ donation** (59% supported the principle of opt out in a 2016 TNS survey¹)

Although, there is little firm evidence that opt out legislation in isolation causes increases in organ donation and transplantation, there is encouraging evidence that, as part of a package of measures, opt out legislation can lead to increases in organ donation and transplantation.

- A body of evidence shows that there is a well-established association between higher deceased donation/transplantation and opt out legislation/systems compared to opt in. Although it is important to note that not all opt out countries have higher rates of deceased donation and transplantation

- A range of before and after studies suggest a change to a system of opt out donation can result in increases in organ donation, although this evidence base is somewhat limited

- A small body of evidence from psychological experiments explains how opt out could increase donation and transplant, although its real world applicability is limited

- It is challenging to separate the impact of opt out legislation from other concurrent system changes, thereby limiting the evidence base

- **There is some encouraging but limited evidence that opt out systems can bring about wider positive changes, which are likely to increase organ donation and transplantation**

- There is a small body of international evidence that suggests opt out is associated with **increased willingness to donate**. People in opt out countries were between 17–29 per cent more likely to report willingness to donate their own organs and 27–56 per cent more likely to authorise the donation of their own relatives' organs, compared to respondents living in opt in countries

¹ TNS Organ Donation 2016 Campaign Evaluation (September 2016, unpublished)

- There is a limited body of evidence with regards to the impact of opt out legislation and systems on the number of people registering decisions on a register (where they are used).
- Existing evidence draws no firm conclusions about the impact of opt in legislation on **family authorisation**. A small number of studies suggest how family authorisation could increase as a result of opt out. However, there is also evidence (e.g. from Chile) indicating decreases in family authorisation
- Welsh evidence suggests that opt out is likely to increase **awareness of organ donation** more widely, although only limited conclusions can be drawn from this
- **There is a strong body of evidence that highlights the importance of non legislative measures, such as improving infrastructure.** This suggests that opt out systems and legislation function most effectively as part of a wider package of measures,
 - **Public awareness** of opt out appears to be important and associated with increased willingness to donate, particularly in opt out systems
 - **Public attitudes** are likely to be crucial. There are several country based case studies (e.g. Brazil) which indicate that negative public attitudes, particularly due to medical mistrust, can pose a risk when implementing opt out. There is strong evidence that families should be encouraged to have **conversations about organ donation** and where this happens it is likely to increase organ donation and transplantation. It is vital that families are aware of what organ donation is, when it can occur and their involvement in the process
 - There is evidence which indicates that **improving health care staff awareness**, knowledge and confidence in relation to donation is likely to be important in raising organ donor numbers
- There are various contextual factors (e.g. mortality rates) that are likely to influence the impact of opt out and these should be considered when comparing countries
- Religion and ethnicity are likely to be important and the relationship with organ donation is complex, **but there was little evidence identified with regards to opt out on specific religious or ethnic groups.**

1. Introduction

1.1 Context

At present, in Scotland, in order to become an organ or tissue donor after death, a person must either have expressed a wish/decision to do so or one of their relatives can authorise donation on their behalf. This system is known as an '**opt in**' system. In many cases, individuals make their decision known by joining the **NHS Organ Donor Register (ODR)**. If an individual has not given authorisation and they could be a potential organ or tissue donor, their nearest relative will be asked to make a decision. However, a nearest relative cannot authorise donation if they know that their relative did not want to donate. Having such sensitive conversations with families at the time an individual dies is very difficult, and, understandably, many families find it impossible to consider such requests when they are often in shock or grieving. In such circumstances a significant minority of families (43.6% in 2017-18) do not give authorisation for donation for transplantation, although survey evidence suggests that the majority of people in Scotland support donation.

Conversely opt out systems presume (or deem) that a person consents to becoming a deceased donor if they haven't actively opted out of donating e.g. by joining an opt out register or otherwise making their decision clear. In a hard opt out system, family members are generally given little if any input to the decision, but most opt out systems have some form of safeguards to allow families to say if they don't think their relative wished to donate – this is known as a 'soft' opt out system. A number of soft opt out systems also exclude certain categories of people, such as children, from being covered by the presumed consent arrangements.

In Wales, a soft opt out system of deceased organ and tissue donation was implemented in December 2015. This continues to allow for potential donors to provide consent themselves, for example by joining the ODR or for a relative to provide consent on their behalf. It also provides for a statutory 'opt out' ODR of people who do not want to donate their organs or tissue. Where an individual has neither opted in nor opted out then their consent can normally be deemed. However, this is subject to certain safeguards, for example checking that family members are not aware of the potential donor having said to anyone that they did not want to be a donor. In addition, children, adults with long-term incapacity and people ordinarily resident in Wales for less than twelve months cannot have their consent deemed.

In England and Northern Ireland, the existing legislative system under the Human Tissue Act 2004 is an opt in system, which is very similar to that in Scotland. However, the UK Government has indicated that it is supportive of proposals to move to an opt out system for England and is expected to publish its response to the recent consultation on opt out shortly. This means that an opt out system may also be implemented in England in the future. There are no current known plans to move to an opt out system in Northern Ireland.

In Scotland, since 2013/2014 there has been an 18% increase in people registering a decision to become a donor after death and the percentage of people on the ODR in Scotland is the highest in the UK (48% as at June 2018²) (NHS Blood and Transplant, 2017). Survey evidence³ suggests that the Scottish public are generally supportive of the principle of opt out. Evidence from the wider UK suggests that support for opt out has been growing over time and is now supported by the majority of the population (Rithalia, et al., 2009). This is further discussed in section 4.6.

This review was undertaken to provide an overview of evidence to inform decision making concerning opt out and its potential implementation.

1.2 Aims

The overarching aim of this rapid evidence review is to explore the evidence of effectiveness of opt out organ donation legislation and systems⁴.

Specifically it aims to examine evidence regarding:

- the effectiveness of opt out legislation and systems in increasing the number of transplants and donations
- contextual factors that are likely to influence organ donation and transplantation
- other non-legislative factors that are positively associated with successful opt out systems and higher rates of organ donation independently of opt out (infrastructure, public awareness/attitudes, family authorisation, staff attitudes and awareness, media campaigns and support for organ donation)
- the potential influence religion and ethnicity could have on opt out.

There is a particular focus on evidence from Wales because it is more comparable than many other countries that have adopted opt out legislation and systems.

² A backlog of registration activity made via GP Services is not accounted for

³ The survey asked “How much do you agree or disagree that everyone should be presumed to be willing to be an organ donor unless they register a wish otherwise” - 59% agreed with this. It was carried out by TNS but has not been published.

⁴ Legislation refers solely to the change in law and presumption that those who do not declare their wishes are deemed to want to donate. The term system is not particularly well defined in the literature, but in this context it refers to the legislation change and the wider media and awareness raising campaigns and staff training that often occur concurrently with the legislation change.

1.1 Methodology

Search strategy

A literature search was conducted by the Scottish Government Library and covered a wide range of resources, including: IDOX; K&E; Web of Science; and ProQuest Databases. The majority of the literature was published within the last few years. Both peer reviewed and non-peer reviewed (grey literature) papers were considered. This was partly due to limited evidence base regarding the impact of opt out. This paper considers much of the research covered in a systematic review for the Welsh Government and also more recent evidence, such as international comparative study by Shepherd et al (Shepherd, et al., 2014).

Peer review

This paper was peer reviewed by researchers external to Scottish Government at NHS Health Scotland.

Limitations

The review was completed in a short timescale, and consequently it is not intended as an exhaustive critical appraisal of the research evidence. There are limitations to the current evidence base which are highlighted throughout. For instance, many international studies do not distinguish between hard and soft opt out systems and their impacts despite the substantial differences in the importance of family views/consent. This limits the extent to which we can generalise these findings to the potential implementation of opt out in Scotland. In addition, there was often a lack of specific evidence with regards to opt out. In this case, inferences have been made from the wider organ donation literature. In the literature that examined the influence of other factors in increasing donation and transplantation, it was often unclear what the most crucial factors were.

A lack of evidence was identified with regards to tissue donation and transplantation and therefore it has not been considered specifically in this review.

2. Effectiveness of opt out legislation and systems

This section reviews the evidence on the effectiveness of opt out organ donation legislation and systems. For the purpose of this review, factors associated with effectiveness of opt out systems and legislation includes the number of organs donated and transplanted. Wider effectiveness factors also include changes in attitude (such as being more supportive about donation and behaviours such as greater discussion with families) and awareness/understanding concerning donation.

Registration to be an organ donor is considered, as it remains important because of its association with increased authorisation for donation. It is not treated as a key measure of effectiveness, as in an opt out system not registering a decision is also considered an active decision to donate.

Generally the ultimate aim of organ donation systems is to maximise the number of successful donations to satisfy demand for organs. Increasing awareness of organ donation is associated with increasing numbers of people registering to donate their organs, which is in turn associated with increasing the number of organ transplants. However, increasing awareness and the number of people on a register (for those countries which have one) does not guarantee an increase in the number of transplants. For instance, any increase in the number of people registering as donors is likely to be followed by a significant time lag in donation increases (as those who are newly registering are unlikely to die in the near future). In addition, in many cases those registering may not represent proportionately those who are most likely ultimately to be able to potentially donate. This is as those on registers tend (based on evidence from the UK) to be higher socio economic groups and (in Scotland) particularly in the 30 to 49 years age groups⁵ (Optimisa Research, 2014), and do not necessarily mirror proportionately the population who tend to be potential deceased donors. Another challenge to consider is that the context in which people can donate organs, as deceased donors, is relatively small as only 1% of people die in circumstances which would make them eligible to donate. It is clear that more people on a register does not automatically result in more donors. Unless figures are examined over long periods of time, this makes it difficult to robustly conclude that any change is as a result of a policy intervention.

2.1 Comparison studies between opt in and opt out countries in relation to donation and transplantation

This section reviews the body of evidence examining the differences between opt in and opt out countries, in relation to willingness to donate, family authorisation, deceased and living donation.

⁵ As well as more likely to be disproportionately White

Opt out organ donation impact on willingness to donate and family authorisation (or willingness to allow donation to proceed)

We explore the association between opt out systems of organ donation on willingness to donate, as this is an important step towards donation. Mossialos et al examined individuals' willingness to donate using survey data from 15 European countries. The study found that those in opt out countries were between 17–29 per cent more likely to report willingness to donate their own organs and 27–56 per cent more likely to authorise the donation of their own relatives' organs compared to respondents living in opt in countries (Mossialos, 2008). Shepherd et al found that family members were much more likely to be willing to authorise the donation of their loved one's organs when they had registered to be a donor themselves (Shepherd & O'Carroll, 2014). The literature regarding family authorisation and opt out could be further developed as only one study was identified. The evidence indicates there is an association between opt out and higher willingness to donate (Mossialos, 2008). A potential causal mechanism for this is discussed in the experimental studies literature (discussed below).

Deceased and living donation and the number of transplants

Deceased donation generally represents the largest source of organs and therefore is particularly important to consider. This section examines the association between opt out and deceased donation/the number of transplants. Shepherd et al (Shepherd; O'Carroll and Ferguson, 2014) conducted a statistical analysis comparing opt in and out countries in terms of both **deceased** and **living donation**. The evidence suggests that deceased donor rates (per million population) were higher in opt out than opt in consent countries. However, they found that **living donation**, which generally represents a smaller source of transplants, was lower in opt out countries. Further evidence to support this was identified by (Bendorf, et al., 2013), who found lower rates of living donation for kidney transplantation in opt out countries. Despite this association, there was limited consideration in the existing literature as to a potential cause and this would benefit from further exploration (Ugar, 2015).

Bendorf (2013) identified that the number of kidneys and livers transplanted from deceased donors was higher in opt out systems, despite lower living donation. Adadie et al examined data from 27 EU countries and found that opt out countries have higher deceased (cadaveric) donation (28% to 32% higher) and kidney transplants (27% to 31%), after controlling for a wide range of factors.

A Welsh Government systematic review compared the number of deceased donors per million population in 2011 across countries (The Welsh Government, 2012). The countries with the smallest number of deceased donors were Bulgaria, Turkey, Cyprus and Greece, all of which had an opt out (presumed consent) organ donation system at the time of the study. However the countries with the greatest number of deceased donors per million population also have opt out systems, such as Portugal, Belgium, Croatia and Spain (The Welsh Government, 2012). Countries with opt out systems therefore did not automatically have high rates of donation.

This suggests that opt out systems are not a guarantee of success and highlights the importance of considering opt out as part of wider package of measures/initiatives.

Overall, despite these exceptions, there is a well-established association between opt out and higher rates of deceased donation across a body of evidence (Abadie, A, Gay, S, 2004) (Ugar, 2015) (Shepherd; O'Carroll and Ferguson, 2014) (Bilgel, 2013). There is also some evidence of an association of greater willingness to donate and higher levels of family authorisation of donation. However this is not sufficient to establish a casual impact.

2.2 Evidence from before and after studies

A range of studies have examined countries before and after the implementation of opt out and these further support the association between opt out and higher donation rates and explore a potential causal impact (The Welsh Government, 2012).

Whilst the studies have become increasingly sophisticated at controlling for a wide range of factors that influence organ donation rates (see for example, Shepherd and O'Carroll, 2014), a limitation of the current evidence base is that legislation changes occur concurrently with other factors associated with opt out legislation, such as increased media campaigning and public awareness. The vast majority of the studies make little effort to investigate the impact of any other changes taking place simultaneously. It is therefore nearly impossible to ascertain if it was the legislation or the changes to the system associated with opt out that had the greatest impact.

Impact on proportion registering to be an organ donor

Registration appears to be an important factor in obtaining authorisation. The Organ Donation Taskforce 2008 report found that 90% of families in the UK allowed donation to proceed when a potential donor had joined the ODR compared to 60% when they had not (Organ Donation Taskforce, 2008). The complexity of this relationship is discussed further in section 4.9. This review could not identify any studies examining the impact before and after the introduction of opt out legislation on the numbers of people registering. However, evidence from the Welsh impact evaluation of opt out is encouraging. This found there has been an increase in those registering on the NHS ODR- 34% of the Welsh population were on the ODR in 2014/2015, compared to 36% in 2015/16 (at the time of implementation of opt out) and 38% in 2017/18.

International evidence that examines the impact on donation and transplant numbers

There is a range of evidence which examines the impact of opt out on organ donation and transplant numbers before and after implementation. However, as some studies measure increases in organ donation using different organ types, comparison between studies is difficult.

Rithalia et al's (2009) systematic review examined five before and after studies from three different countries (Austria, Belgium and Singapore), and concluded that there was an increase in deceased donation in all of these studies. The Belgian study is the most relevant as it is the only one where a **soft opt out system** applies. However, it is limited by the length of time that has passed since the introduction of opt out in 1986. The study identified that kidney transplantation from both **deceased and living donors** increased from 18.9 to 41.3 per million population per year over a three year period after the change in legislation (Roels, 1991).

Austria and Singapore both have **hard opt out systems**, where family members do not have a say about the use of a loved one's organs. Comparisons to soft opt out are limited due to the significant differences in authorisation between hard and soft opt out. The Singapore study found that kidney donation increased from 4.7 to 31.3 per million population in the three year period after a change in legislation (Rithalia, et al., 2009). In Austria there was evidence of an increase of 4.6 to 10.1 donors per million population per year in the four years after the introduction of presumed consent. The largest increase in Austria was 27.2 donors per million population (pmp) in the five years after the introduction of infrastructure changes (such as full time transplant coordinators). The study therefore supports the premise that a change to hard opt out legislation can increase organ donation, but continues to support the evidence base that other factors are important. There are limitations generalising these findings to soft opt out legislation.

In the international evidence base, there is variation in the size of increase in deceased donation rates. For instance, some studies report opt out legislation is associated with increases in deceased organ donation rates of 13–18 % (Bilgel, 2013) and 25–30% (Abadie, A, Gay, S, 2004).

Overall, these studies support the notion that changes in systems to an opt out system increase the number of people registering a decision and making people more aware of organ donation policy (this is further supported in the evidence from Wales, discussed below). It is important to note that the literature did not distinguish if this difference was due to the availability of an organ donor register or awareness of organ donation as a whole. There is also firm evidence of an association between opt out and higher deceased donation rates. However, this evidence is insufficient to conclude that opt out legislation in isolation causes higher donation rates. As discussed above, these studies are limited by the concurrent changes that occur to support opt out legislation as part of a wider opt out system. In addition, further research is required to examine the specific impact of soft opt out, as only

one study from the international literature was specifically identified which examined this area.

In summary, it is likely that opt out systems and the often concurrent changes are likely to contribute to increases in organ donation. It is challenging to establish if the legislation in isolation leads to increases from the current evidence base, partially because of the other changes that occur concurrently.

2.3 Welsh impact evaluation

Whilst there are key differences (donation rates, proportion of the population on the ODR) between organ donation in Wales and Scotland, the similar context⁶ makes it a useful example to examine in detail. The Welsh impact evaluation (The Welsh Government, 2017) examined the impact of opt out legislation and associated system changes three years after implementation. Due to this short timescale, it is challenging to draw any firm conclusions on the overall impact of opt out, but there are some clear changes already apparent.

Public awareness

Overall there was increased awareness of the change to the opt out policy among both NHS staff and the general public. For the public, this has been associated with increased support for opt out. However, awareness had recently decreased, highlighting the importance of maintaining continuous awareness campaigns when implementing opt out.

Whilst this increased awareness is encouraging, it is impossible to tell if this change is a result of opt out legislation or concurrent changes. In addition, it is challenging to establish the long term impact of the opt out system because the evaluation was undertaken only a short time after the implementation of the legislation.

Organ Donor Register (ODR)

The increased publicity campaigns associated with opt out in Wales are likely to have contributed to the number of people opting out on the ODR (it was possible to opt out on the ODR from six months before the introduction of opt out in Wales). In 2014/2015, 0% of the population opted out of the ODR (as the option was not available). This rose to 5% in 2015/2016 and 6% in 2016/2017 (NHS Blood and Transplant, 2017). This slight increase suggests that people are able to make an informed decision about whether or not to opt out. Evidence based on approaches to families upon the death of a loved one, have however shown that a significant proportion of others have not opted out via the ODR, but their family members have declared that their relative did not want to donate. This suggests that conversations

⁶ Scotland and Wales are both devolved nations in the UK, which are part of a wider UK system of organ donation and are culturally similar.

are often happening in the family, even if individuals are not always recording their decision on the ODR. Awareness of organ donation throughout Wales is, therefore, increasing due to the change in legislation and associated campaigns, which have been associated positively with successful opt out systems (The Welsh Government, 2017).

Family consent

In Wales, analysis from the consent data has shown an increase in the percentage of cases where there was consent for donation (either deemed consent, express consent where the patient was on the ODR or consent from a nearest relative). Consent rates have risen from 44% in 2014 to 65% in 2018.

Number of transplants

Given that organs are allocated UK wide, many organs transplanted in Wales will come from donors in other parts of the UK, so robust conclusions cannot be drawn from any change in transplant numbers in Wales. The Welsh impact evaluation notes that it is too soon to establish any impact on transplantation numbers (The Welsh Government, 2017). Transplantation trends have not been consistent since the implementation of opt out. In 2013/14 the total number of transplants in Wales was 208, at the point of the introduction of the new opt out legislation the number of transplants increased to 214 however the following year the number of transplants decreased to 187 (NHS Blood and Transplant , 2017).

Summary of Welsh evidence

Although there is strong evidence to suggest an increase in people on the ODR, public awareness and consent rates in Wales, it is impossible to infer that the legislation *alone* has increased these elements directly. This is likely to be due to a number of additional changes that have also occurred as part of a wider system change, such as awareness raising campaigns. There is evidence to suggest that opt out legislation *coupled with the wider changes to the system* have impacted positively on many important factors that promote organ donation in Wales. It is crucial to highlight that, due to the modest numbers of organ donors, it is too soon make any conclusions with regards to impact on donation. In this regard, it will be of particular importance to continue to monitor the impact on deceased donation in Wales.

2.4 Experimental studies

As the Welsh Government (The Welsh Government, 2012) identified, there are a range of psychological experimental studies that highlight how opt out may cause an increase in donations. These studies suggest that in an opt out context individuals attribute and perceive less of an individual and personal cost to donating their organs. This evidence indicates that simply framing organ donation as the default increases individuals' willingness to donate (Davidai, 2012) (Dalen, 2014). Whilst these studies provide valuable insights into how opt out may contribute to

increased willingness to donate, the findings are of limited value when translating them to the real world due to the artificial settings that these psychological experiments took place in.

2.5 Overall conclusion on international evidence of effectiveness of opt out

International evidence highlights that opt out *systems* can be effective as part of a wider package of measures (discussed in further depth below). However, overall the body of evidence that examines that opt out *legislation* in isolation causes increases in donation and transplant lacks robustness and is sparse.

Nevertheless, the broader evidence, particularly from Wales, suggests that a move to an opt out system and the associated changes (e.g. increased media awareness raising) is likely to impact positively on many important factors that promote organ donation (public awareness, numbers on the ODR and deemed consent/authorisation rates). Legislation is likely to be a catalyst for other beneficial changes in the wider system.

3. Additional factors associated with increasing organ donation

This review aimed to provide a broad and brief overview of other factors (independent of legislation) that might contribute to increased organ donation and transplantation.

3.1 Contextual factors

Contextual factors account for some of the differences in the effectiveness and impacts of opt out systems observed between countries. Contextual factors include the infrastructure supporting organ donation; investment in healthcare; public attitudes to and awareness of organ donation; the population's age distribution; and causes of death. The last two factors are particularly important in determining the potential number of donors available (Rennick, 2015). Rithalia et al., (2009) found in at least one study that mortality from road traffic accidents, gross domestic product per capita, religion (Catholicism), education and health expenditure per capita were associated with high organ donation rates.

4. Factors associated with successful opt out legislation

This section examines the evidence on factors that have been associated with successful opt out legislation. However it is important to note that many of these studies are limited as they are based on association rather than cause and therefore the results should be treated carefully.

4.1 Family support and the role of family

The following section provides a brief overview of evidence about the role of the family in organ donation and how this could potentially be improved further.

In both opt in and soft opt out systems the family⁷ can play a central role in ensuring that organ donation is successful. Indeed, the Welsh Government conducted an international evidence review of the role of families and concluded that it was one of the most crucial factors in promoting organ donation and ensuring that it takes place (The Welsh Government, 2012). This is particularly true where the deceased has made no clear wish/decision with regards to organ donation as the decision often falls to the family. Even where a clear wish has been expressed by the deceased to donate, the family can in practice still overrule this (although there is no legal right for them to do so, clinicians would be unwilling to proceed against the family's wishes). Indeed, in Scotland in around 1 in 10 cases in 2017/18 where a patient had joined the ODR, their family members would not allow the donation to proceed (Walker, et al., 2013). Nonetheless, authorisation rates in Scotland and the rest of the UK (including in Wales following the introduction of opt out) are continually significantly higher where the patient was on the ODR than where they were not. This suggests opting in will remain an important factor in deciding whether or not donation is authorised, regardless of whether there is an opt in or opt out system.

The literature highlights numerous ways to improve how families can be involved in organ donation and how to raise rates of authorisation. One of the central elements of this is awareness by the family of their loved one's wishes. There is clear evidence that demonstrates that the families are much more likely to authorise organ donation when the wishes of the deceased are well known (Walker, et al., 2013) (Sque & Long, 2003). Use of the ODR plays a key role here, which will be further discussed in section 4.9. As concluded by the Welsh Government, a crucial element to increasing awareness of an individual's wishes is to promote and improve family conversations. Key strategies for doing this have been to make

⁷ The use of the term family has been used for simplicity and is referred to in its broadest sense. This includes non-blood relatives and extends to the 'nearest and dearest'.

family conversations easier, more attractive/timely and by highlighting the social benefits of being a donor (The Welsh Government, 2012).

The discussion process informing a family's decision on whether to proceed with donation is highlighted consistently as an important factor in increasing the proportion of families allowing donation to proceed and ensuring an informed decision. Increasing understanding of the organ donation process and addressing concerns with regards to disfigurements of the deceased have both been highlighted as important. There is also evidence of the importance of involving specialist, trained staff in conversations, particularly at an early stage (Sque & Long, 2003). In addition to this confidence in staff and previous experience of the health care professional is essential (The Welsh Government, 2012). Ultimately families have to be both educated about organ donation and content with the processes before organ donation can proceed.

4.2 Impact of soft opt out on family authorisation

As stated above, in soft opt out systems the decision of the family is one of the most important factors in influencing donation. The evidence base is fairly limited in examining the potential impact of opt out on family authorisation. (Sque & Long, 2003) conducted an unrepresentative survey and found that the vast majority of respondents felt that opt out would promote conversations amongst family members. As previously discussed, there is also encouraging evidence from the recent Welsh impact evaluation, where consent rates have increased since the introduction of opt out, although it is impossible to establish if this is due to opt out directly. However, a Dutch experimental study conducted in a laboratory setting indicated that when authorisation was presumed by staff that family consent for donation was actually lower. Caution should, however, be applied when applying these results to the real world.

Overall the evidence base is mixed, but there is clearly encouraging emerging evidence from the fairly comparable context of Wales. The impact of opt out and the associated changes on the proportion of cases where families respect their loved one's decision (whether that is deemed or express self-authorisation) should become clearer over time here and it will be important to monitor these closely.

4.3 Infrastructure

Infrastructure improvements that support organ donation and transplant appear to be important factor(s). For example, Spain has one of the highest rates of organ donation in the world and operates an opt out system. Whilst there are a range of complex factors that have contributed to this result, infrastructure changes are believed to have made an essential contribution to increasing organ donation and transplantation. For example, it was a decade after implementation of opt out in Spain that donation rates began to rise; this occurred concurrently with the establishment of new infrastructure (Organ Donation Taskforce, 2008). Further evidence to support the importance of infrastructure comes from certain regions of Italy, who adopted a similar model of Spanish infrastructure saw organ donation double (Willis, 2014). One study claims that the biggest increase in organ donation, under opt out, in Austria, was driven by infrastructure changes, such as the use of

full time transplant coordinators (Rithalia, et al., 2009). In 2008 the UK Organ Donation Taskforce at the time prioritised improvements in infrastructure over a move to opt out, implementing a range of changes based on the models used in Spain. Overall it is clear that high quality infrastructure is crucial regardless of the type of organ donation system in place.

4.4 The importance of public awareness

Public awareness of opt out also appears to be an important factor in increasing willingness to donate in opt out systems.

An international comparison study found that when people were aware of their nation's legislation, the proportion of people who were willing to donate their organs was greater in opt out (85.2%) than opt in (81.7%) countries. By contrast, when people were not aware of their nation's legislation, there was no difference in people's willingness to donate their organs in opt in (58.6%) and opt out (59.2%) countries (Shepherd, et al., 2014). A robust study by Mossialos et al (2008) found that greater awareness of the legislation was associated with an increased willingness to donate both your own and a family member's organs at an individual level (Mossialos, 2008). In Chile there was a decrease in family authorisation, which is likely to have driven subsequent falls in donation following the implementation of opt out legislation (Dominguez, 2013). A key factor cited is that 70% of the population were unaware of the legislation change (amongst other factors, such as actual and perceived corruption). This is however based on case study evidence of limited robustness.

The Welsh Government has invested in public awareness raising campaigns to support the implementation of opt out. Before implementation in 2012, approximately 60% of the public were aware of the pending legislation change. This increased after implementation to a peak of 84% in 2016 (The Welsh Government, 2017). However, the Welsh impact evaluation found that this had dropped slightly in 2017. This highlights the importance of continued awareness raising campaigns.

Whilst further robust evidence is required to firmly establish this, there is overall encouraging evidence to suggest that awareness of the legislation is likely to be a significant factor in ensuring an effective opt out system. Therefore robust regular monitoring of public awareness will be important to support a potential opt out system.

4.5 The importance of public attitudes towards opt out

There is some limited evidence that indicates public attitudes to opt out systems are likely to be an important factor that contributes to the effectiveness of opt out legislation to increase deceased donation. Several case studies (Shepherd, et al., 2014) (Organ Donation Taskforce, 2008) have cited the significance of a lack of public support (which was caused by a range of varying factors) for opt out, where the legislation was not effective. In France⁸ there was significant negative media coverage of opt out legislation when the corneas were removed from a young man,

⁸ This is referring to the 1992 introduction of opt out legislation

despite medical professionals acting within the law. Moreover, the Brazilian Government had to withdraw their opt out legislation due to public concerns (Csillag, 1998). The negative public attitudes in these nations were seen as being due to mistrust towards medical professionals and this was possibly one of the key concerns of the UK Organ Donation Taskforce, which recommended that opt out should not be introduced in the UK. This remains unclear as Shepherd et al (2014) highlight that further empirical evidence is needed to determine if public attitudes and medical mistrust vary between opt in and opt out countries (Shepherd; O'Carroll and Ferguson, 2014). Nevertheless, it is important to consider the potential risks opt out poses in terms of trust in the NHS.

The Welsh Government systematic review highlighted the importance of public attitudes in effectively increasing organ donation (The Welsh Government, 2012). Regular monitoring of attitudes is therefore an important consideration. Strategies to encourage people to donate (such as media campaigns) and public education are seen as beneficial in addressing concerns and fostering positive public attitudes (Wright, 2007).

4.6 Public attitudes in Scotland and the UK towards an opt out system of organ donation

As mentioned in the introduction to this report, the majority of adults in Scotland are likely to be supportive of the principle of opt out. A recent (2016) TNS omnibus survey found that 59% agreed that “everyone should be presumed to be willing to be a donor unless they register a wish otherwise”⁹. As previously mentioned UK surveys suggest attitudes to opt out have improved over time, however there is no clear Scottish data to establish a trend. In 2004 a survey indicated that 53% of the Scottish population opposed doctors automatically being allowed to take organs for transplant (Haddow, 2006), but generalisations are of limited relevance to the soft opt out system proposed in Scotland.

Rest of the UK

There is a wider range of data available at the UK level. A range of surveys show that, at this level, support for opt out has been increasing over time. Before 2000, it was likely that the majority did not support opt out legislation, but since then support has increased to an average of 60% as shown by a systematic review of four studies (Rithalia, et al., 2009) (Coad, et al., 2013).

To support the implementation of opt out, the Welsh Government has conducted multiple surveys of public attitudes. In 2012, before implementation, 49% supported opt out and this had risen to 71% by 2016. The recent 2017 impact evaluation concluded that support for the soft opt out system remained high (The Welsh Government, 2017). At the time of writing this review the UK government was analysing but had not published the results of its own consultation on opt out organ donation and therefore this analysis was not available.

⁹ TNS Organ Donation 2016 Campaign Evaluation (September 2016, unpublished)

Attitudes of ethnic and religious groups

Whilst there is broad support for opt out, it is important to note likely differences between certain groups. Key differences by religious and ethnic group are further explored in section 5.

4.7 Staff training, attitudes and awareness

Medical staff play a particularly prominent role in increasing organ donation (Glasper, 2018). This section therefore examines medical professionals' attitudes and awareness, as well as how to support them in the implementation of opt out. It primarily draws on the findings from the Welsh impact evaluation of opt out, but also examines the international context. Where possible, distinctions are made between staff that work directly with organ donors and their families, and staff that do not (although much of the literature does not make this distinction).

This review identified no existing data with regards to Scottish NHS staff attitudes towards opt out systems of organ donation. There is a need for further research here and it is recommended that the Scottish Government continues to monitor this as it becomes available. It did however identify a significant amount of research on Welsh NHS staff.

The Welsh Government commissioned a survey to explore the attitudes and awareness of NHS staff in Wales due to the change. A baseline survey was conducted pre and post implementation (which covered a wide range of staff, not just those involved in donation). A majority of staff supported the change before implementation (71%) and this increased to 89% post implementation. The survey also identified that most staff felt the move to opt out would have little impact on them. Staff awareness of the change was fairly high before implementation (89%) and increased to 96% post implementation (The Welsh Government, 2017). Both awareness and self-related knowledge increases were highest amongst staff that did not work directly with organ donors (e.g. GPs and nurses outwith critical care units). The increase in both awareness and attitudes highlights the importance of information campaigns in educating staff not familiar with organ donation to increase awareness.

There were several key findings from the Welsh impact evaluation that highlighted how staff could be supported. It stressed the importance of ensuring that NHS staff have a clear understanding and good level of knowledge of the new opt out system. Despite high levels of awareness the report highlighted that NHS staff benefited from further training, such as in approaching the organ donation conversation with the family (The Welsh Government, 2017) (although this would only be relevant for staff working in critical care areas). A high emphasis was placed on this, with continuous monitoring recommended.

International evidence also supports the notion that training of key health service staff is important to support the change to and implementation of opt out. Research conducted in Belgian hospitals found that confidence, along with knowledge, is important in effectively communicating with families about the organ donation process. Increasing staff knowledge and improving their confidence may lead to a

higher authorisation rate (Pelleriaux, et al., 2008). Sula et al (2012) found that education, donor management and how to communicate with families should be part of the specialist training of health care professionals (Smudla, et al., 2012). Further to this, a Greek study also found that staff education for health service staff was also key to gaining support from the public and increasing organ donation (Symvoulakis, 2014).

Therefore from the international evidence it is clear that communication and knowledge is important to support legislation and system change. Ultimately when there is staff support, there is more likely to be a greater understanding of organ donation amongst families and thus donation is more likely to be authorised. The evidence base highlights the importance of continuous training and education to support the implementation of opt out.

4.8 Communication and media campaigns

This section examines the evidence regarding the use of media campaigns to raise awareness and educate the public about opt out. Media and communication campaigns are an essential way of raising the profile of organ donation and are frequently used to raise the profile of organ donation more widely. The Welsh systematic review concludes that where opt out legislation is implemented, communication and campaigns are likely to be important factors in the legislation's success (The Welsh Government, 2012).

There is a limited evidence base about how media and communication campaigns for organ donation can be improved and this is an area where further research is needed. A study by Cameron et al (2013), in the US, describe a move to use Facebook to raise awareness of organ donation (online). They reported that the organ donation rates in the US were very low and after the Facebook campaign began there was an increase in the number of people who registered to be a donor. This increase was seen in the 12 days following the campaign (Cameron, et al., 2013).

Another US study looked at using written letters to raise awareness of their register (Feeley, Quick and Lee, 2016). The letters were sent to select parts of the American adult population, with some letters sent by state officials and others not. They found that overall the letters alone outperformed brochures (as well as use of a combination of brochures and letters). Registration rates were higher when direct mail letters were written by officials affiliated with state departments. Feeley et al (2016) reported that this was an inexpensive campaign and was beneficial for increasing the number of people registering. Encouraging people to register is still important in opt out as it is likely to increase authorisation to donate.

4.9 Use of an organ donor register

This section examines the evidence regarding the use of a register to increase organ donation and support opt out. As highlighted, increased registrations do not equate proportionately to increased donations and, in opt out systems, not registering your wishes is considered an active choice to donate. We have chosen to consider the impact of opt out on the register as registering one's decision is

likely to increase authorisation for donation and therefore eventually the number of successful donations.

As discussed in section 1, Shepherd et al found that family members were much more likely to be willing to permit the donation of their loved one's organs when the patient had registered to be a donor (Shepherd & O'Carroll, 2014). In general, the number of people signing up to the register is positively associated with a higher number of organ donors in soft opt out countries. For instance, Bigel (2010) found that use of a dual register (where someone can both opt in or opt out as opposed to only opting in) was positively associated with a higher number of donors (Bigel, 2013).

Nevertheless, this relationship is more complex than it first appears. Bigel (2010) also identified that in hard opt out countries, that not having a register was also positively associated with higher number of donors. For soft opt out systems, only use of a dual register¹⁰ was positively associated with higher number of donors. For example, a single registry¹¹ that still required family authorisation was not associated with an increase in deceased donation rates. Both hard and soft opt out systems have the potential to be successful and this study highlights the probable importance of the interaction between family support and ODR type.

The evidence examined suggests that use of a dual ODR is likely to be beneficial in soft opt out systems. However, it is important to highlight that these studies only identify an association and therefore any conclusions about a causal impact are highly limited. Again, further robust research is needed to establish the interaction between ODR types and opt out systems. It is also important to highlight that Ugar found that individuals are much less likely to register their preferences on the ODR in presumed consent countries (Ugar, 2015). This suggests the continued importance of promoting the use of a register in opt out countries.

¹⁰ An organ donation register where you can both opt in and out

¹¹ An organ donation register where you can only opt in or opt out but are unable to do both.

5. Opt out – ethnicity and religion

5.1: Rationale and context

This section aims to provide a summary of the evidence on the potential impact that opt out could have on specific ethnic and religious groups. A wider search was undertaken for a range of protected characteristics (e.g. disability, age). This was to assess any potential uneven impacts of opt out on particular groups and to support potential mitigation strategies. Ethnicity was selected for this summary as there is a greater need for organs (particularly kidney) from certain minority ethnic groups as the best match for a kidney is from someone within the same ethnic group. Waiting times for kidneys in particular are normally longer for people from minority ethnic groups, who have a higher risk renal failure. For example, the average wait for a White patient is approximately two years for a kidney, whereas for Asian and Black patients it is over three years (NHS Blood and Transplant , 2017). This is thought to be driven partly by greater demand due to a predisposition to several health conditions that result in kidney failure. It is also driven by supply shortages: in the UK, there is a lower proportion of people from minority ethnic communities on the ODR. In addition, families belonging to minority ethnic groups are less likely to authorise donation and have less positive attitudes regarding organ donation generally (Optimisa Research, 2014).

This is particularly important as in the UK demand for organs from minority ethnic donors has increased by approximately 57% over the last five years, faster than in the general population (NHS Blood and Transplant 2016, 2016). For Scotland, this may be of growing importance as the minority ethnic population continues to increase. Moreover, organs are shared throughout the UK. For example, an organ from Scotland could be transplanted into someone in Wales. Therefore Scotland could be impacted by the overall supply of organs from minority ethnic donors in the UK, although the number of people from minority ethnic groups waiting for an organ in Scotland is proportionately lower than that in England.

Religion was examined in more depth than other characteristics for several reasons:

- Partly due to its partial interaction with ethnicity
- The evidence base for religion (and ethnicity) is more developed than for other characteristics
- There is clearer evidence regarding a potential impact of religion on organ donation

5.2 Minority ethnic groups

Attitudes of minority ethnic groups towards opt out and organ donation more widely

This section examines evidence with regards to the attitudes of ethnic groups as the literature identifies that some of these groups are likely to hold particularly different attitudes from the general population. It is well established in the UK that minority ethnic groups tend to be less supportive of organ donation generally and have greater concerns about it. At a UK level in 2014, support amongst minority ethnic groups for organ donation is lower than in the general population (44% vs. 86%) and only 28% state that they would consider donating their own organs compared to 82% of the population (Optimisa Research, 2014). No evidence was identified on the attitudes of minority ethnic groups towards opt out and this is an area that requires further research. However, given this lower overall support, it is not unreasonable to assert that there is likely to be less support for opt out overall.

Impact of opt out on minority ethnic groups

We did not identify any direct evidence of the impact of opt out legislation or systems on minority ethnic groups. We recommend continued monitoring of this area of research as it develops. This review therefore examines some of the wider literature analysing the impact of ethnicity on organ donation and attempts to make inferences where possible, which should be considered within these limitations.

Impact on the organ donation registration by minority ethnic communities

There is no specific evidence of the impact of opt out on registration on the organ donor register by people from ethnic minorities. However it is not unreasonable to assert that opt out provides an opportunity for increased targeted awareness raising campaigning, which could be used to target minority ethnic groups, in particular to encourage the registration of their wishes. Conversely the evidence presented on religion presents some potential barriers, which could make minority ethnic groups who hold those religious views more likely to opt out in response to the new systems.

Impact of opt out on the authorisation of potential donors from minority ethnic communities

In Scotland, authorisation rates remain much lower for deceased minority ethnic donors relative to the general population. For instance, after neurological death, authorisation rates were 74% for white patients compared to 35% for minority ethnic patients. A smaller, but still significant, difference was observed for donation after cardiac death (DCD) authorisation rates: 61% and 31% respectively (NHS Blood & Transplant 2016). Improving authorisation amongst minority ethnic groups clearly remains an important continuing challenge.

No evidence was found concerning the impact of opt out on authorisation rates for minority ethnic groups. It is possible that it could lead to an increase through

deemed authorisation and more positive conversations with medical staff. However, there is also the risk that due to a range of factors (poorer knowledge, less positive attitudes, greater concerns around organ donation), that a move to opt out could result in levels of authorisation remaining similar or decreasing. We recommend that future research is monitored.

5.3 Religion

Attitudes of religious groups towards opt out

There is evidence which suggests that religion is likely to be a key influence on decisions about organ donation, although the impact is likely to vary within and between religious/faith groups.

Evidence was identified that explored the attitudes of religious groups towards opt out. Interviews with UK leaders of the main faith and belief organisations were carried out on behalf of the 2008 Organ Donation Taskforce. They found that the majority of faith leaders supported an opt in system, and preferred retaining it to the opt out system (Randhawa, et al., 2010), which only a few participants supported. Whilst this could provide some indication of potential views of religious populations themselves, it is important to note that these views do not necessarily represent the views of those populations. Indeed, the relationship appears to be complex and varies by religion. Indeed, religion could interact positively with opt out with some religious groups in certain contexts. For instance, the six countries with opt out policies that have the highest number of donors on a register (ranging from 66-94%) are Catholic (Mone, 2017). However, numbers on the register are not necessarily an indicator of an effective opt out system and there was no firm evidence identified that being Catholic firmly impacts individuals decisions regarding donation.

Attitudes of religious groups towards organ donation more widely

This section aims to draw inferences from the wider literature on attitudes to organ donation as a whole. A study of Muslims of Pakistani origin and white English nationals (a spectrum of religious and non-religious groups) living in the North of England carried out in 2003 found differences between Muslim and White English groups in terms of the influence of religious belief on attitudes and views towards organ donation. In particular, for Muslims, there was a strong emphasis on understanding Islam's position when considering decisions about donation. In contrast, concerns relating to religion were not reflected in the views of white English individuals, where issues relating to a lack of trust in the medical profession or a fear that doctors might not try so hard to save their life, were more common concerns (Haward, 2003). Focus groups with a cross section of Black African and Caribbean populations in South London also identified religion as a factor influencing the decision to agree to become an organ donor or not (Davis, 2006).

These findings have been replicated more recently in mixed methods research commissioned by NHS Blood and Transplant (Optimisa Research, 2014). Another study by Sharif et al (2011) surveyed Western Muslims (British, European, North American and Oceanic geography) on attitudes to organ donation and found that only 26% of respondents agreed with the concept of presumed consent (or 'opt out'). This compared with 55% who did not, and 20% who did not know (Sharif, et al., 2011).

In both the qualitative and quantitative research, Muslims were much more likely to mention religion as a key influence on any decision about organ donation, and to reflect on whether or not Islam allows or forbids this. In contrast, other faiths were more concerned by issues such as lack of trust or personal concerns (Optimisa Research, 2014). In addition to differences between religious or faith groups, there is often a lack of consensus within these groups on the issue of organ donation (Sharif, et al., 2011). Although the official positions stated by each of the key religious groups in the UK are broadly supportive, and none formally oppose organ donation (NHS Blood and Transplant 2016, 2016), religion is still often viewed as a barrier (Davis, 2006). Overall, studies have been more likely to identify religious opposition to organ donation (23 studies) than religious support (10 studies) (Oliver & Ahmed, 2011).

Overall the evidence in this section suggests that the views amongst key religious leaders/organisations about opt out seem to be particularly important because of the influence of religion in decisions about organ donation amongst individuals of faith (particularly Islam). It is possible that some people from particular faith groups could take a stance encouraging people to opt out. This suggests a need to continue to work with key opinion leaders¹².

¹² An Equalities Impact Assessment was conducted by Scottish Government with regards to how to mitigate these barriers for religious and ethnic groups.

6. Conclusions

This report aimed to provide an overview of the evidence about the effectiveness of opt out systems and legislation.

- **There is encouraging evidence that as part of a package of measures opt out can lead to increases in organ donation and transplantation**
- **However there is little robust evidence to suggest that opt out legislation *in isolation* leads to increased donation and transplantation. The intention in Scotland is to introduce opt out in addition to the wider package of measures in place.**
- **There is some encouraging evidence from Wales to suggest that opt out *systems* can positively influence increases in factors that are associated with higher donation**, such as public awareness, registration of wishes and family support for donation. However, it is too soon to draw any firm conclusions from this evidence
- **It is clear from the evidence the importance of non-legislative measures which can increase organ donation in their own right. This suggests that opt out systems function most effectively as part of a wider package of measures.** There are also wider contextual factors that are likely to cause differences between countries regardless of the type of legislation. There are several key non-legislative measures that are likely to support opt out in increasing organ donation:
 - **Raising public awareness and understanding is crucial.** There was some robust evidence to suggest that this public understanding and awareness increases with opt out, this is likely due to wider system changes and publicity campaigns. It is crucial to gain support for the legislation change from the public and also medical staff. Without support, the legislation change is less likely to be effective
 - **The role of the family and authorisation is also important.** The evidence with regards to the impact of opt out on family involvement and authorisation is limited, but evidence from Wales is encouraging. Further evidence is required to firmly establish this. Regardless, families should continue to be encouraged to have conversations about organ donation
 - **Raising NHS staff awareness, knowledge and confidence** will impact on the number of successful organ donations and support an opt out system. Further to this, specialist nurses should also approach the subject early with the family and the evidence suggests that adequate training and awareness is essential in supporting this

- **Increased registration and discussion of wishes is important.** Whilst opt out presumes consent when no wishes are stated, the evidence suggests that registration remains important as it encourages and gives families the confidence to allow donation to proceed. Therefore registration of wishes should be continued to be promoted and encouraged under an opt out system.
- **The evidence indicates that religion and ethnicity are important and the relationship with organ donation is complex.** There was little direct evidence identified with regards to opt out. However, the wider evidence regarding organ donation suggests that there could be particular concerns amongst certain religious groups. A targeted approach towards religious and faith groups is likely to be beneficial in advance of implementation. This would increase their understanding of what the change in legislation is and minority ethnic groups would be more likely to have conversations about organ donation. The move to opt out presents an opportunity for further engagement in this area

Overall there are positive indications to suggest that opt out legislation can contribute to increasing deceased donation and transplantation as part of a package of wider measures. A change in legislation is often accompanied by additional factors, such as campaigns and additional training for health staff that can raise understanding and awareness of organ donation. It is clear from the evidence that both context and non-legislative measures are important in the success of organ donation systems.

7. References

- Abadie, A, Gay, S, 2004. *The impact of presumed consent legislation on cadaveric organ donation: A cross country study*. p. 1064.
- Bendorf, A., Pussel, B. & Kelly, J. a. K. H., 2013. Socioeconomic, demographic and policy comparisons of living and deceased kidney transplantation rates across 53 countries. *Nephrology*, 18(9).
- Bilgel, F., 2013. The effectiveness of transplant legislation, procedures and management. *Health Policy*, 110(131), pp. 229 - 242.
- Bruce, C. & Koch, P., 2017. Flawed Assumptions: Ethical Problems With Proposed Presumed Consent Legislation. *American Journal of Transplantation* , 17(12), pp. 3262- 3263.
- Burra, P. & De Bona, M., 2007. Quality of life following organ transplantation. *Transplant International* , 20(5), pp. 397- 409.
- Cameron, A. M. et al., 2013. Social Media and Organ Donor Registration: The Facebook Effect. *American journal of transplantation* , 13(8), pp. 2059- 2065.
- Coad, L., Carter, N. & Ling, J., 2013. Attitudes of young adults from the UK towards. *Transplantation Research* , 2(9).
- Cox, R., 2016. *Survey of Public Attitudes to Organ Donation: Wave 10, 11 and 12*, Cardiff: Welsh Government .
- Csillag, C., 1998. Brazil abolishes 'presumed consent' in organ donation. *Lancet*, Volume 352 - 1367.
- Dalen, H, 2014. Comparing the effects of defaults in organ donation systems. *Science and Medicine*, Volume 106, pp. 137 - 142.
- Davidai, S, 2012. The meaning of default options for potential donors. *PNAS*, 109(38), pp. 15201 - 15205.
- Davis, C., 2006. The influence of religion on organ donation and transplant amongst the Black Caribbean and African population - a pilot study in the United Kingdom. *Ethn Dis*, Volume 1.
- Dominguez, J., 2013. Presumed Consent Legislation Failed to Improve Organ Donation in Chile. Volume 45.
- Glasper, E., 2018. Increasing Organ Donation for Children Who Need Transplants. *Adolescent Nursing*, 41(1).
- Glendinning, R. & McHugh, S., 2017. *Evaluation of the Human Transplantation (Wales) Act: NHS Wales Staff Survey Wave 2*, Cardiff: Welsh Government.
- Haddow, G., 2006. "Because You're Worth It?" The Taking and Selling of Transplantable Organs. *Journal of Medical Ethics*.
- Harel, I., Kogut, T., Pinchas, M. & Slovic, P., 2017. Effect of media presentations on willingness to commit to organ donation. *Proceedings of the National Academy of Sciences of the United States of America* , 114(20), pp. 5159-5164.
- Haward, C., 2003. The meanings of organ donation: Muslims of Pakistani origin and white English nationals living in North England. *Soc Sci Med*, Volume 3.
- Hutchings, P., Grey, P., Manchipp, S. & Phelps, C., 2013. *Understanding public attitudes towards organ donation: A media analysis*, Cardiff: Welsh Government .

- Mone, T., 2017. With Renewed Calls for Presumed Consent, Let's Look at the Donation and Transplant Rates of Opt-In vs Opt-Out Countries. *Transplantation* , 101(11).
- Mossialos, E, 2008. Does organ donation legislation affect individuals' willingness to donate their own or their relative's organs?. *BMC Health Services*, 8(48).
- NHS Blood and Transplant 2016, 2016. *Organ and Tissue Transplantation for Black, Asian and Minority Ethnic (BAME) communities. Report for 2015/16*, s.l.: s.n.
- NHS Blood and Transplant , 2017. *Organ Donation and Transplantation: Activity Report: 2016 and 2017*, s.l.: s.n.
- NHS Blood and Transplant , 2017. *Statistics about organ donation*. [Online] Available at: <https://www.organdonation.nhs.uk/supporting-my-decision/statistics-about-organ-donation/> [Accessed 17 October 2017].
- Oliver, M. & Ahmed, A., 2011. Donating in good faith or getting into trouble: Religion and organ donation revisited. *World J Transplant*, Volume 2.
- Optimisa Research, 2014. *BAME organ donation 2014: gaining a deeper understanding of attitudes, cultural and lifestyle influences and behaviours towards organ donation within BAME communities in the UK*, s.l.: s.n.
- Organ Donation Taskforce, 2008. *The potential impact of an opt out system for organ donation in the UK*,
- Palmer, M. & Jones, I., 2012. *Opt-out systems of organ donation: International evidence review*, Cardiff: Welsh Government .
- Pelleriaux, B. et al., 2008. An analysis of critical care staff's attitudes to donation in a country with presumed-consent legislation. *Prog Transplant*.
- Randhawa, G. et al., 2010. 'Opting-in or opting-out?'—The views of the UK's faith leaders in relation to organ donation. *Health Policy*, 96(1), pp. 36- 44.
- Rennick, L., 2015. *Transplantation (Authorisation of Removal of Organ Etc) (Scotland Bill): SPICe Briefing*, s.l.: s.n.
- Rithalia, A. et al., 2009. A systematic review of presumed consent systems for deceased organ donation. *Health Technology Assessment* , 12(26).
- Roels, 1991. Three years of experience with a 'presumed consent' legislation in Belgium: its impact on multi-organ donation in comparison with other European countries. The Leuven Collaborative Group for Transplantation.. *Transplantation Proceedings* , 23(2), pp. 903-904.
- Rudge, C. & Buggins, E., 2012. How to Increase Organ Donation: Does Opting Out Have a Role?. *Transplantation*, 93(2), pp. 141-144.
- Sharif, A., Nightingale, P. & Lipkin, J, 2011. A Qualitative Survey of Western Muslim Attitudes to Solid Donation. *Transplantation*.
- Shaw, D. et al., 2017. Family Over Rules? An Ethical Analysis of Allowing Families to Overrule Donation Intentions. *Transplantation* , 101(3), pp. 482- 487.
- Shepherd; O'Carroll and Ferguson, 2014. An international comparison of deceased and living organ donation/transplant rates in opt-in and opt-out systems: a panel study. *BMC Medicine*, 12(131).
- Shepherd, L. & O'Carroll, R., 2014. When do next-of-kin opt-in? Anticipated regret, affective attitudes and donating deceased family member's organs. *Journal of Health Psychology*, 19(12), pp. 1508-1517.

- Shepherd, L., O'Carroll, R. & Ferguson, E., 2014. An international comparison of deceased and living organ donation/transplant rates in opt-in and opt-out systems: a panel study. *BMC Medicine*, Volume 12.
- Smudla, A., Hegedus, K., Mihay, S. & Szabo, G. a. F. J., 2012. The HELLP concept - relatives of deceased donors need the Help Earlier in parallel with Loss of a Loved Person.. *Ann Transplant*, 17(2).
- Sque, M. & Long, T. & S., 2003. *Organ and tissue donation: exploring needs of families. Final report of three-year study commissioned by the British Organ Donor Society*, Southampton: University of Southampton.
- Sque, M. et al., 2008. The UK postmortem organ retention crisis: a qualitative study of its impact on parents. *Journal of the Royal Society of Medicine*, 101(2), pp. 71-77.
- Sudan, D. et al., 2014. Quality of Life after Pediatric Intestinal Transplantation: The Perception of Pediatric Recipients and Their Parents. *American Journal of Transplantation*, 4(3), pp. 407- 413.
- Symvoulakis, E, 2014. rgan Donation Knowledge and Attitudes among Health Science Students in Greece: Emerging Interprofessional Needs.. *International journal of medical sciences*, Volume 10.
- The Welsh Government, 2012. *Opt-out systems of organ donation: International evidence review*,
- The Welsh Government, 2012. *The role of families in organ donation: International evidence review*
- The Welsh Government, 2017. *Evaluation of the Human Transplantation (Wales) Act: Impact Evaluation Report*
- Thomas, S., Milnes, S. & Komesaroff, P., 2009. Understanding organ donation in the collaborative era: a qualitative study of staff and family experiences. *Internal Medicine Journal* , Volume 39, pp. 588- 594.
- Ugar, Z., 2015. Does presumed consent save lives? Evidence from Europe. *Health Economics*, Volume 12, pp. 1560 - 72.
- Walker, W., Broderick, A. & Sque, M., 2013. Factors Influencing Bereaved Families' Decisions About Organ Donation: An integrative literature review. *Western journal of nursing research* , 35(10), pp. 1339- 1359.
- Willis, B. a. Q. M., 2014. Opt-out organ donation: on evidence and public policy. 107(2).
- Wright, L., 2007. Is presumed consent the answer to organ shortages? No. *British Medical Journal* , 334(7603).

8. Glossary

BAME	Black, Asian and Minority Ethnic
CLOD	Clinical Lead for Organ Donation
authorisation	Give permission for something to happen (in this case deceased donation)
Deceased donation	<p>Deceased donation includes:</p> <ul style="list-style-type: none"> • Brain stem death - This is where a person no longer has activity in their brain stem due to a severe brain injury. They have permanently lost the potential for consciousness and the capacity to breathe. This may happen even when a ventilator is keeping the person's heart beating and oxygen is circulated through their blood. • Circulatory death - Is the irreversible loss of function of the heart and lungs after a cardiac arrest from which the patient cannot or should not be resuscitated. It can also be the planned withdrawal of life-sustaining treatment from a patient within the Intensive Care Unit or the Emergency Department.
Living donation	Whilst you are still alive you can choose to donate a kidney, a small section of your liver, discarded bone from a hip or knee replacement and also your amniotic membrane (placenta).
ICU	Intensive Care Unit
NHS BT	National Health Service Blood and Transplant
opt in system	An informed or explicit consent system
opt out system	A presumed consent system (a more detailed definition is provided in the text)
organ donation	The process of removal and transplantation of viable organs from a living or deceased donor

	to recipient
organ donor register (ODR)	Organ Donor Register: A confidential list of people who want to donate, or not donate, their organs and/or tissue
SNOD	Specialist Nurse for Organ Donation



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