



# **The Human Tissue (Authorisation) (Scotland) Act 2019: Qualitative Research with NHS Staff involved in Donation, October 2019 - January 2020**



**HEALTH AND SOCIAL CARE**

# The Human Tissue (Authorisation) (Scotland) Act 2019:

## Qualitative Research with NHS Staff involved in Donation, October 2019 - January 2020

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Lilian Kennedy, PhD

Health and Social Care Analysis Division, Scottish Government

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## Abbreviations

CLOD	Clinical Lead for Organ Donation
ED consultant	Emergency Department consultant
ICU consultant	Intensive Care Unit consultant
ICU senior nurses	Intensive Care Unit senior nurses
NHSBT	NHS Blood and Transplant
ODR	Organ Donation Register
SNOD	Specialist Nurse for Organ Donation
TDC	Tissue Donation Coordinator

## Executive Summary

This report forms part of the baseline information underpinning the five year [Monitoring and Evaluation Plan](#) of 'The Human Tissue (Authorisation) (Scotland) Act 2019' (hereafter referred to as 'the Act', 'the law' or 'the legislation'). The Act introduces a system of 'deemed authorisation' for organ and tissue donation for transplantation. This means that if someone dies in circumstances where they potentially could become a donor, and they have not recorded a decision on donation, they would be presumed to be willing to donate unless their family provides information that the potential donor was unwilling to do so.

This report presents the findings from qualitative research undertaken between October 2019 and January 2020, with 63 NHS staff involved in organ and tissue donation across Scotland (via 28 one-to-one interviews and 9 focus groups). Report findings focus on NHS staff's awareness of, knowledge about, and attitudes toward the Act, organ and tissue donation, current donation procedures, changes that will be made to this process once the law goes into effect, as well as training sessions to support NHS staff's delivery of these changes.

Note that the findings presented here do not cover all aspects of the Act or the infrastructure to support it, and some discrepancies may arise between staff views in advance of the Act's implementation and the exact stipulations of the legislation.

### Key Findings

- Most NHS staff interviewed were supportive of the move to an opt-out donation system, though a majority did not predict that the change would dramatically increase authorisation or donation rates. Instead, most felt that the law change would support current practices, which were described as in line with the goals and practices inherent in an opt-out system. Many felt confident that current practices allow for the facilitation of as many appropriate authorisations of donation and organ and tissue donations possible. ICU staff members in particular illustrate that they were largely "not worried" about the move to an opt-out authorisation system.
- By majority, the NHS staff members interviewed were very supportive of organ and tissue donation generally, while also recognising that donation is a challenging experience for all involved. Across the different staff groups, support for donation was grounded in the views that:
  - Organ and tissue donation can positively impact donor families' lives.
  - Patient choice is supported with donation as a standardised option in end-of-life care.

- Supporting a patient's choice to pursue donation can save, or improve, the life of a transplant recipient.
- By majority, NHS staff members felt that the implementation of the Act could bring about positive impacts to the donation system in Scotland. Staff grounded their support in the views that:
  - The legislation's publicity campaign could positively raise the profile of donation generally, and tissue donation more specifically.
  - Publicity of the law change could prompt more people to register their wishes on the Organ Donor Register, which could make conversations about donation with a patient's family easier.
- NHS staff members also highlighted difficult aspects of donation and concerns about the implementation of an opt-out system. The main topics raised were:
  - Some NHS staff have concerns that potential donors and their families lack understanding about what donation entails, in that the donation process can be an emotionally exhausting experience for patients' families.
  - Many staff were clear that a high priority in the move to a deemed authorisation system is maintaining patient and patient family trust in the NHS and donation processes.
  - Some staff were concerned that a deemed authorisation will diminish the voluntary 'gift' connotation of donation.
  - A small number of staff worried that implementation of an opt-out system could be counter-productive to aims of increasing donation numbers for reasons centring on members of the public feeling pressured to donate and so acting in the opposite way.
- Staff felt that successful early identification and referral of potential donors, and successful authorisation processes can best be supported in a number of ways:
  - Greater visibility of Specialist Nurses for Organ Donation (SNODs)<sup>1</sup> and Clinical Leads for Organ Donation (CLODs)<sup>2</sup>.
  - Good relationship between a SNOD and clinical staff in charge of patients and who speak with patient families.
  - Consultants feeling that the rapport they have built with families is appreciated by SNODs as donation processes progress.

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<sup>1</sup> Specialist Nurses-Organ Donation support potential donor families and the operational processes of organ donation. The specialist nurse receives detailed training in communication and family support, especially in the end of life wishes conversations. Further information can be found on the [NHSBT website](#).

<sup>2</sup> The primary roles of CLODs is to provide clinical leadership within the hospital, to champion and promote the value of deceased organ donation. Further information can be found on the [NHSBT website](#).

- Increased and earlier education of staff involved in ICU (Intensive Care Unit) and ED (Emergency Department) settings about donation, such as within NHS sites via SNOD/CLOD/TDC activities and within medical training of younger consultants.
  - The experience of being a part of a 'successful donation' process can buoy staff confidence.
  - Getting positive feedback from NHSBT (NHS Blood and Tissue) about practice, such as rates of missed opportunities to refer to SNODs and letters from donor and transplant families.
- NHS staff identified key items to address in trainings/events aimed at NHS staff about the law change<sup>3</sup>. These key items included:
    - Clarification of the legal stipulation of 'deemed authorisation'.
    - A number of staff expressed an interest in about learning about the key messages in the public marketing campaign.
    - Consultants, in particular ICU consultants, were interested in ways in which more communication between ICUs could be supported so that 'best practices' and 'problem solving' techniques regarding donation developed within different health boards/other sites could be shared across different teams.
    - A large number of consultants suggested that signposting that 'SNODs are the experts – it's best to always refer to them when in doubt' alongside case studies where working with SNODs has proved beneficial would be helpful in creating consistent inclusion of SNODs across sites. In line with this, a smaller number of consultants requested clarification about research showing that SNODs 'in the room' during end-of-life conversations correlates with higher authorisation rates, as a few mentioned conflicting evidence on this finding.
    - Consultants hoped for greater clarity on 'duty to inquire'<sup>4</sup> stipulations, expressing varying levels of confidence in their understanding of what this practice entailed and how it would affect families in practice. Some staff suggested the inclusion of a different 'duty to inquire' scenarios in the training sessions to remain confident that families' wishes would be taken into account in authorisation conversations, and that trust in the

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<sup>3</sup> This feedback has helped to inform NHS Training plans.

<sup>4</sup> The [Organ and tissue donation - authorisation requirements: guidance](#) explains that under the Human Tissue (Authorisation) (Scotland) Act 2019[1] ("the 2019 Act"), duty to inquire is a core principal that requires that health workers should make every effort to establish the decision or views of the potential donor, and then to support their decision being fulfilled. Please note that this guidance was published after research interviews took place.

ICU/NHS would not be damaged by deemed authorisation conversations.

- ED and ICU consultants and nurses also highlighted the need for greater awareness raising of tissue donation among ED staff, with 'clear, simple guidelines about how to speak with families' of the recently deceased to increase ED staff's confidence in raising this topic.



## Introduction

This report presents the findings from qualitative research undertaken with NHS staff involved in donation processes, in relation to the 'The Human Tissue (Authorisation) (Scotland) Act 2019' (hereafter referred to as 'the Act', 'the law' or 'the legislation'). The Act introduces a system of 'deemed authorisation' for organ and tissue donation for transplantation. This means that if someone dies in circumstances where they potentially could become a donor, and they have not recorded a decision on donation, they would be presumed to be willing to donate unless their family provides information that the potential donor was unwilling to do so. The Act is predicated on the views of the donor taking primacy.

A five year [Monitoring and Evaluation Plan](#) is in place that outlines the outcomes that the Act is expected to influence and the data sources that will be used to measure progress. The primary aim of the Act is to increase donation authorisation rates, alongside a package of supporting implementation activities to raise awareness, knowledge, skills, and support for the legislation and opt-out authorisation processes. A number of the Act's intended outcomes relate specifically to the views, confidence, and practices of staff who are involved in donation. Correspondingly, some of the implementation activities focus on NHS specialist staff recruitment, engagement, and training.

In order to understand the potential impact of the legislation, [baseline information was collected prior to the Act's implementation](#). Existing data on organ and tissue donation in Scotland was primarily quantitative (e.g. donation rates or public attitudes). This information did not give insights into NHS staff perspectives or the landscape of donation processes that can affect donor referral or authorisation processes. This research fills an evidence gap about the views held by NHS staff involved in donation about donation generally, and the move to a deemed authorisation system more specifically.

It is important to address this gap because research on organ and tissue donation systems outside Scotland shows that, alongside a transition to an opt-out authorisation system, infrastructure improvements appear to be important factors in contributing to increased organ donation and transplant rates (Organ Donation Taskforce, 2008; Rithalia et al., 2009; Willis, 2014). In addition, international research shows medical staff play a prominent role in increasing organ donation rates (Glasper, 2018). More information from the international data can be found in the Annex.

This report presents findings from qualitative research conducted with NHS staff about their awareness of, knowledge about, and attitudes toward the Act, organ and tissue donation, current donation procedures, changes that will be made to this process once the law goes into effect, and training sessions support NHS staff's delivery of these changes. The data presented in this report addresses the specific workforce related outcomes in the Monitoring and Evaluation Plan. Note that the findings presented here do not cover all aspects of the Act or the infrastructure to support it, and some discrepancies may arise between staff views in advance of the Act's implementation and the exact stipulations of the legislation.

The findings of this report are based on 28 one-to-one interviews and 9 focus groups conducted with 63 NHS staff involved in organ donation across Scotland. The research was carried out between October 2019 and January 2020. Further information on the types of professionals interviewed is provided in the section on methods and sampling.

## Research Questions

This report presents the findings in relation to the following research questions:

1. What are NHS staff members' views on, understanding and awareness of the new opt-out authorisation system?
2. What are NHS staff's views on the NHS organ and tissue donation system, and donation as part of end-of-life care?
3. How can successful early identification and referral of potential donors, and successful authorisation processes best be supported? What supports a reduction in missed donation opportunities? What are barriers to the successful realisation of these aims?
4. What are key areas that training should target to raise awareness and knowledge of, and support for tissue and organ donation, and opt-out authorisation among NHS staff?

It is important to note that due to the nature of qualitative research, findings outwith the scope of the above questions emerged, and have been reported on in this report.

## Methods and Sampling

This research uses a qualitative approach as it allows for a deeper understanding of the contextual factors grounding the experience, views, and perspectives shared by participants. A qualitative approach also ensures that the context of different specialist NHS staff roles within the larger donation process can be considered, so that a multifaceted understanding can be created based on the findings of this project. Interviews and focus groups also allowed the researcher to ask follow-up questions so participants could clarify and reflect on their insights into the donation process and opt-out authorisation, thereby producing clearer, more comprehensive, and contextualised data.

Interviews and focus groups were conducted in person by a Scottish Government researcher, between October 2019 and January 2020, on or near NHS sites to create as minimal inconvenience to NHS staff as possible. Project participants were interviewed individually or in focus groups, and asked to discuss: their role within the donation process; what helps and hinders them in this role; their understanding of, knowledge of, and views on donation and opt-out; and their approach to authorisation from families for organ and tissue donation, and referral of potential donors to

SNODs/TDCs. The aim was to identify some of the factors which play a role in the success of the donation process, specifically those which affect missed opportunities of donor referral, and donor family authorisation rates.

In this report, the term 'NHS staff' refers to all of the staff groups, listed below, who participated in this project. 28 one-to-one interviews and 9 focus groups were conducted across Scotland with:

- 8 Clinical Leads for Organ Donation (CLODs)
- 10 Specialist Nurses for Organ Donation (SNODs)
- 23 Intensive Care Unit (ICU) consultants
- 15 ICU nurses
- 2 Emergency Department (ED) consultants
- 1 ED nurse
- 4 Tissue Donation Coordinators (TDCs)

The initial sampling aim was to gain equal representation of staff from both ICU and ED contexts. However, a greater number of those working within ICU settings, than ED settings were recruited for the study. This is due to contextual issues of the ED work setting. Due to the nature of emergency medicine, ED staff members' work patterns are unpredictable and it is challenging for them to schedule reliable time periods for interviews or focus groups. As such, only a few ED staff contacted the researcher of this project expressing interest and availability for participation at NHS sites during their work hours. Indeed, 2 of the 3 ED staff who participated did so during their off-hours. Further, as explained by the ED staff that were able to provide interviews, ED settings do not have as robust of an infrastructure around facilitating donation as ICU settings do, such as lead consultants for organ donation or embedded SNODs to maintain and promote awareness of donation within the department.

### Data Analysis Approach

The interviews and focus groups were audio recorded (with permission from the participants) and professionally transcribed. The transcripts were analysed using a content analysis approach, with use of the NVivo qualitative data analysis software programme. The data was systematically organised (into themes and categories) so that the similarities and differences between participants' responses could be compared. The content analysis approach is well suited to analysing nuanced information about organisational procedures and social phenomenon, and fits with the type of data collected by the interviews and focus groups and with the purpose of this research, namely producing key insights about NHS staff's differing values, understandings, and perceptions. Further information on the content analysis process can be found in the Annex. Findings are presented thematically, in relation to the

different research questions, and quotations from interviews and focus groups are used to illustrate key points.

## Ethics

A Research, Innovation and Novel Technologies Advisory Group (RINTAG) Service Evaluation application (ODT Study N#9) was submitted for ethical approval prior to the start of this qualitative project. Ethical approval was obtained on 26 September 2019 from the Transplant Quality Improvement Group, NHS Lothian, and on 15 October 2019 from the Research, Innovation and Novel Technologies Advisory Group (RINTAG) of the Organ Donation and Transplantation Directorate of NHS Blood and Transplant (NHSBT).

## Research Findings

This report's findings are organised into three sections, relating to the themes of the research questions that underlying the qualitative study. Each section presents key findings which arose from interviews and focus groups within that theme. Where applicable, it also describes any differences in the views of the different groups of staff who participated.

### Section 1: Staff views and understanding of donation and the opt-out authorisation system

This section relates to research questions 1 and 2:

1. What are NHS staff members' views on, and understanding and awareness of, the new opt-out authorisation system?
2. What are NHS staff's views on the NHS organ and tissue donation system, and donation as part of end-of-life care?

#### **Key Findings:**

- Most NHS staff interviewed feel that current donation practices already broadly match the goals and practices inherent in an opt-out donation authorisation system.
- NHS staff members are very supportive of organ and tissue donation while also recognising that donation is a challenging experience for all involved.
- NHS staff feel that implementing an opt-out authorisation system in Scotland could have positive impacts, such as raising public awareness and support for donation and encouraging people to register on the Organ Donation Register (ODR).
- NHS staff members highlighted difficult aspects of the donation process, which centred on the long duration that donation processes can take and the impact of this on families and staff.
- NHS staff members want to ensure that a move to an opt-out authorisation system is done well so that patient and patient family trust in the NHS is maintained.

## 1a. Most staff feel that current donation practices match those inherent in an opt-out system

The research questions underlying this study made a distinction between the current organ and tissue donation system and that which is anticipated after the move to the implementation of an opt-out donation authorisation system in Scotland. However, this distinction was much less apparent in discussions with NHS staff. The majority of NHS staff members interviewed expressed support for, or neutral feelings about, a move from the current opt-in authorisation system for donation to an opt-out donation system. However, the majority of NHS staff did not feel that a move to an opt-out authorisation system would significantly change the majority of key donation processes or practices, such as identifying a patient as a potential donor, referring that patient to a SNOD/TDC, broaching the topic of donation with patient families, or the donation authorisation conversation with patient families. Differences in views about the change to an opt-out system did arise within different NHS staff groups, as described below.

### CLODS, ICU Consultants, and ICU nursing staff

In general, ICU consultants and ICU nurses felt that a shift to an opt-out authorisation system would not greatly impact the current donation processes, whereas staff working within Emergency Departments, or SNODs were more likely to predict impacts of the change. Indeed, a large number of ICU consultants expressed the hope that significant changes would not be made to current donation processes as currently practices were describes as in line with the goals of an opt-out system. For example, an ICU consultant commented:

“I would hope that actually it's not going to cause too much of a change of practice because I would like to think that we're actually doing a lot of these things - they are routine already.” (ICU consultant)

The predominant reason for this anticipated lack in changes to donation processes, was grounded in staff views that current practices already mirror the goals of an opt-out authorisation system, in that every potential patient is identified, SNODs are contacted about potential donors, and that almost every patient family is given the opportunity to consider donation as an end-of-life care option. The following quotations illustrate the views expressed:

“I'm not against an opt out [system], I'm just not entirely convinced it will make a difference because...unless they [a patient family] said they don't want to, we approach everyone anyway whether they are on the organ donor register or not. I just don't see why it [the move to an opt-out system] will increase it [donation rates].” (ICU consultant)

“...the dynamic or the process will probably change a little bit, but not a huge amount to be honest with you, because you're going to still have to speak to an organ donation nurse to talk about the process. And so they're going to have to be involved in the process at some stage anyway.” (ICU consultant)

‘...from my point of view the way that I would approach things will be essentially the same...Perhaps I might phrase my questions slightly different in that I would say I am obliged to now ask [about donation and/or if they wish to speak with a SNOD]. Something like that...I always said that it's my duty to ask in this situation so whereas now it would be perhaps I might just rephrase. So I don't think that from my perspective on a one to one patient or family discussion, that the law change is going make a huge difference to me.’ (CLOD)

Many ICU nurses also expressed the view that the opt-out law would not greatly impact their day-to-day work. They described their main responsibility as caring for the patient and supporting patient families, which was cast as separate from the consultants' responsibilities to have conversations with families about donation and authorisation. Many explained that the change in authorisation system would more likely impact conversations with families about donation, and therefore was less likely to affect their nursing practice. Several nurses did however comment that a change in the legislation might result in families “asking about it [donation] themselves...more often,” resulting in nurses alerting the ICU consultants about a family's queries more often. A more detailed discussion of anticipation of a potential increase in families' awareness of, and questions about, donation is discussed in section 1c.

These views expressed by ICU staff members illustrate that they were largely “not worried” about the move to an opt-out authorisation system, in so far as they felt confident that their current practices allow for the facilitation of as many appropriate organ and tissue donations as possible. These comments also underline ICU consultants' general confidence in their knowledge about “what opt-out actually means” as most felt assured in comparing current donation practices to those anticipated in post-implementation of the new legislation. Variations in confidence about their comparative knowledge did emerge, mostly having to do with “the specifics of the law” such as legal stipulations or complex authorisation situations, among others, which are discussed further in section 3.

## SNODS

Akin to other NHS staff groups, SNODs also largely felt that a change to an opt-out donation system was unlikely to drastically change their current practice, especially as it related to conversations they had with patient families or the ICU team(s) they worked with. Like ICU consultants, SNOD interviewees felt that their approach was already in line with their understanding of the aims of an opt-system, in that the option of donation is discussed with every patient family, all information about donation is provided to that family, and that their work with families and within ICU setting works to normalise donation as an end-of-life care option. As one SNOD explained:

“I know that the law is obviously changing, but I don't think the core essence of our conversation is changed. I mean, our core part of our conversation [when speaking to a family] is to make sure they know what they're agreeing to or agreeing not to do, and making sure that they've got the full information to make the choice.” (SNOD)

The majority of SNODs were also careful to describe the importance of a “non-coercive” approach to authorisation conversations with families. They also spoke of plans to continue with this approach post-implementation of the Act both because “donation might not actually be right for everyone’s situation” and “shouldn’t go ahead at ‘all costs’”, but also because they felt a non-coercive approach correlates with high authorisation rates. A few SNODs explained that they had high consent rates because this approach helped families understand that they were there to support them “during a difficult time and decision”. As such, this “took some of the pressure off” conversations SNODs had with families about donation, allowing families to consider donation on their own terms and in consideration of patient wishes, as opposed to feeling that “we’re [SNODs] talking them into anything.”

SNODs linked this to creating a better environment for donation authorisation conversations (if families agreed to discuss the topic), which involved questions that could feel “intense” and “invasive” for some families, such as questions about a patient’s history. Many SNODs felt that a non-coercive approach was also appreciated as good practice by their ICU colleagues, and in many conversations, SNODs linked this approach to family conversations with successful and trusting working relationships with ICU staff.

In line with this, SNODs explained that trust built between ICU staff and SNODs encouraged ICU consultants’ referral of patients to SNODs to check for donation eligibility and speak with patient families, when ICU staff felt that a patient was unlikely to survive. As such, SNODs did not think that their approach to family conversations would or should change post implementation of the Act.

A number of SNODs felt that this continuity of practice would be particularly important considering their new ‘duty to inquire’ responsibility under the opt-out



system. SNODs described this duty as an extended investigation into a patient's opt-in, opt-opt, or lack of registration on the ODR to determine a patient's true wishes and "ascertain true deemed authorisation". SNODs explained that ICU staff referring "every patient" to a SNOD, would be necessary to a successful opt-out system "because we'll [SNODs] have to check every time," under 'duty to inquire'. Therefore, keeping to approaches that encouraged referrals was linked to the success of the implementation of the Act.

While the majority of SNODs did not anticipate nor encourage changes to their approach to conversations with families or working relationships with ICU staff, they did anticipate changes related to the medical tests and procedures undertaken on a donor to assess the condition of their organs (termed in the Act as 'pre-death procedures'). In discussions about changes to these procedures, SNODs described their lack of clear insight into what form procedures might take as well as concern about this lack of clarity. However, this concern was often couched in an understanding that these procedures are "being worked out" and that guidance and training would be given prior to the implementation.

In a few cases SNODs did raise concern about what they as SNODs might be permitted to do or not to do in line with new guidelines of the opt-out donation system and the ways in which changes to the procedures might impact on the donation process overall. For example:

"And I think that's probably where our angst lies - what tests we are allowed to ask for. Because, you know, things could significantly delay the length of the process if we're not allowed to do certain things until after we have full authorisation from the family..." (SNOD)

In many cases, SNODs were concerned about the difficulty a 'longer process' might have on patient families, a theme discussed further in section 1d.

## Emergency Department

This section focuses on the views of those in Emergency Department (ED) settings. It should be noted that these interviewees comprised a very small proportion of the overall sample. It must be noted that ED staff who participated in the study variously identified themselves as being "very pro-donation", having a "pet interest in raising the profile" of donation, and interested in "seeing where we can consider donation more often" in ED contexts and standards of practice. On a few occasions, these ED staff explained that their particular interest in donation was more pronounced than other ED colleagues because staffs' encounters and ability to "consider donation" with dying patients are impacted by "the nature of ED medicine". Therefore, this small, self-selecting sample may not represent the overall views on and awareness of donation across ED clinical staff overall who were not reached as part of the

recruitment methods, or chose not to participate for various reasons. However, due to the lack of evidence regarding the views, attitudes, and perspectives of ED clinical staff involved in, or potentially involved in donation, a full discussion of findings is included here.

Similar to their ICU colleagues, ED consultants and nurses felt that a drastic change to practice was unlikely, however, the ED staff interviewed were more enthusiastic in describing how the new law could be “very helpful” in prompting greater awareness of, and discussion of, donation as an end-of-life option in ED settings. ED staff explained that the context of the ED made “donation as a frequent topic of discussion” with patient families or between colleagues difficult. They described how their time with patients was limited, and their medical duties and meetings often needed to conform to clinically pressing, time-sensitive needs, and competing demands. They explained that the unfortunate circumstance in which an ED patient died often arrived quickly and did not often allow for end-of-life care conversations or discussions about donation with patient families prior to death so that donation procedures “could be put in place in time.”

Interviewees related ED departments’ higher tissue donation (as opposed to organ donation) rates to the difference in timelines between the two donation processes. Interview conversations illustrated that preparing a patient (who has been determined as unable to survive) for organ donation is rarely possible in an ED context, however arranging for patient families to be asked about tissue donation and put in contact with a TDC post death was more feasible. In addition, it was explained that ED units have a “high turnover rate”, which meant that specific unit cultures or standards of practice/support for donation were challenging to coalesce. Further, their attention and time after a patient’s death was often immediately needed for another patient, and as such, they were often not able to have longer conversations with families or follow-up “to raise the question of tissue donation”. As such, ED interviewees felt that donation as part of end-of-life care was often not an “ingrained part of practice” or “something that consultants [in ED units] think about.”

The challenges of ED contexts described were often discussed in connection to potential opportunities created by a change to an opt-out authorisation system, which could help to raise the profile of donation within ED departments, and create opportunities for more standardised practices, tools, and education sessions to promote “just thinking about donation” in “hectic” ED contexts. While an ED consultant explained that “I don’t see drastic change happening all at once”, all three ED participants were hopeful that a change in the law would instigate more ED consultants and nurses to raise the topic of donation with families after death, “even if it’s just to ask if a tissue nurse (TDC) can call them.” As such, those working in ED contexts saw any changes to clinical practice that might occur as being incremental, and focussed most on making staff consideration of donation a consistent part of end-of-life care. Most explained that a change in legislation, and its related staff training might also address what they felt was colleagues’ “lack of confidence” about

raising the topic of donation with families. This view, and others related to the views on training is discussed in greater detail in section 3.

In summary, NHS staff view the most direct and significant impacts of the law as having less to do with their current practice, and instead felt that the impacts of this law change will be seen “on the public level”. This was described as changes in levels of public awareness, knowledge, and impacts on the public’s views about donation more generally. Many staff pondered how “shifts in the public [opinion]” would impact on conversations and relationships with future patients and patient families. As the following discussions of this report unpack, a large number of staff anticipated seeing changes in the expectations of patient families about end-of-life conversations and families’ own discussions about end-of-life wishes. Many felt that in turn, these shifts could impact NHS practice “from the ground up”. These views are further detailed in section 1c.

## 1b. Staff are supportive of donation while recognising its challenges

During interviews, staff members overwhelmingly expressed positive support for organ and tissue donation generally, and felt that organ and tissue donation should be an end-of-life care option for patients and patient families within the NHS. Many staff members also described their units as possessing a ‘culture’ of donation support, and most considered this to be part of a trend of increasing support for donation over the past decade.

At the same time, the majority of staff members were clear to highlight that their feelings of support for donation were complicated because many aspects of the donation process are challenging and difficult for patient families and staff alike. Many NHS staff explained that their primary aim was, above all, to respect the experience and grief of patient families during the end-of-life period of their family member. As a self-identified ‘pro-donation’ ICU consultant described:

“getting it right for the family and feeling like you've done the right thing by them for me, at any rate, is one of the most important parts of this. I don't want to feel that, yes, we got two kidneys, a liver and a pair of lungs, but I've completely ruined this family's experience of grief, so I think getting the detail right is essential.” (ICU consultant)

This quote illustrates a view expressed by staff across all interviews and focus groups with all NHS staff groups: patient and patient family care was a central topic of discussion and named as their paramount concern when considering donation in an end-of-life care situation, and in contemplating a transition to an opt-out authorisation system. This attention to patient and patient family care and experience run through the most frequently named aspects of organ and tissue donation which

staff linked to their positive views about donation and potential benefits of moving to an opt-out system, as well as which aspects of donation and opt-out they highlighted as the most challenging.

The following sections detail the reasoning behind staff's positive views on donation and opt-out, as well as their concerns.

## Donation can positively impact donor families' lives

Many NHS staff members highlighted that “often families do take a lot of comfort and a lot of solace in the future from having been able to donate” *and that* organ and tissue donation can also offer emotional comfort to families “during a tragic and difficult time.” For example, an ICU consultant explained that:

“I think there's a perception [among patient families] that it's a really important thing to do. And I think what families get out of it is amazing...most families report back to us that having known some good has come out of - it's been good.” (ICU consultant)

Another benefit highlighted was the added levels of support that SNODs are able to provide to families who decided to move forward with donation. A CLOD explained that:

“the donor families get more support. They get the organ donation nurse with them through the process. They get follow up letters and offers of support for them. That's something that we attempt to do with all our bereaved families but they definitely get more from the NHSBT addition. And so if nothing else, they're getting more interaction from support services.” (CLOD)

ICU staff in particular saw this as a positive, in line with a pervasive commitment to patient and patient family care, and links with views that donation and its requisite processes are an important part of the ICU procedures and care.

While staff members highlighted that donation could bring comfort and solace to families, others were careful to point out that this benefit was not necessarily immediate during the process of donation. During a focus group, a SNOD described that:

“when we are looking after them, they're going through their worst-case scenario. It's an absolute nightmare for them and some of them at the time do say I'm glad that this [donation] can happen, but some of them are just very quiet. And you see them mourning and you see them very upset, but you don't see them getting any benefit from it at the time.” (SNOD)

Interestingly, some NHS staff described that those families that were “sure” about donation and felt confident that “this is what he [dying patient] would have wanted”

often found more comfort during the donation process than those families that had never spoken about member's donation decisions before. This points to potential benefits to patient family comfort and solace which may be gained if the implementation of the donation opt-out legislation instigates the normalisation of conversations about donation wishes between family members prior to circumstances in which NHS staff discussion donation with them in clinical settings, after a tragic event.

## Patient choice is supported with donation as a standard option in end-of-life care

Many NHS staff felt that considering the wishes of a patient and discussing donation with families was an important way to support choice during the difficult period of end-of-life care. This was framed this as in line with NHS staff members' prioritisation of patient and patient family care and experience, as well as following a shared decision-making model of care. An ICU consultant explained that:

“[i]f you are somebody who could potentially be considered as an organ donor, I view that as an individual choice. In the same way that dying at home, dying in hospice, all those other things, having music, having lavender, whatever your thing is, it's an end of life choice. And that's [donation] something that we can facilitate as an end of life choice, because ultimately for all ICU doctors, we're doing it for our patient...”  
(ICU consultant)

NHS staff members, particularly consultants in the ICU and ED, cited the importance of the ODR (Organ Donor Register) when seeking to support patient choice. The usefulness of the ODR was cited in many interviews and support groups, in particular in those with ICU consultants, when speaking about preparing for an end-of-life conversation with the patient family. For example, a CLOD explained:

“Yes, it's a very powerful message to deliver to families. I think if someone is a potential donor and they're on the organ donation register, it frames the conversation very differently. Because what you're saying to families is we're able to fulfil their wish. As opposed to asking the families, do you think they would want this?” (CLOD)

This comment is similar to many made by staff members, which highlighted that “being able to come to them [families] with this piece [registered choice on ODR] of information” seemed to result in less stress for families in many instances, as they might not know their family member's view on donation and therefore feel unprepared to “choose for them”. Other staff also mentioned that knowing that a patient registered a wish to be a donor gave them a “place to start” in discussing donation with families. While most staff explained this was easiest when a patient

had registered a pro-donation wish, others explained that if a choice had not been registered, having “checked” the ODR and consulted with a SNOD allowed them to start an “informed” conversation with family.

Some staff members had experience working in Wales, where the opt-out system for donation was implemented in 2015. One ICU consultant who had this experience explained:

“I know some people would have concerns that the new legislation makes patients feel coerced, families feel coerced, that the state is ‘stealing their organs’ or the state is ‘claiming right to your body’, but in practice, I did not see any of that at all. I thought it was done in a very sympathetic way and I didn’t see any pressure to coerce a family and didn’t see anyone feel uncomfortable with it. If the family expresses no interest, particularly with it being a soft opt out, the organ donation services completely stand back.”  
(ICU consultant)

Importantly, while many interviewees described themselves as being ‘pro-donation’, staff made it clear that which choice – whether to authorise donation or not – was much less important to them than knowing that patient choice had been ascertained, families had been consulted, and their views respected. For example:

“the outcome does not really matter as long as the family has made the right decision for them, for the patient, I’d like it to be a yes, but as long as we have done things appropriately, if it’s a no, that’s actually fine.” (CLOD)

“...it’s [donation] not for everyone - at end of the day it’s a personal choice so you [staff members] don’t get too wrapped up in people who say no because it’s obviously the right reasons for them.” (SNOD)

## Donation can save, or improve, the life of a transplant recipient

Staff members also tied their positive views of donation to the lives that an organ or tissue donation might save or enhance. As one SNOD said “It’s a good thing, [it] helps save people’s lives.” Another SNOD explained:

“...when I am called to the unit I know that the family I am going to speak to will be heartbroken but I can’t change the outcome there, but if they go down the road of organ donation we can at least make someone else’s lives better. I can’t change people dying but I can change the outcomes in terms of improving the lives of significant others. So that is my main driver for the job I do.” (SNOD)

In a few focus groups with a range of staff members, participants commented on the benefit of hearing from transplant recipients either in the form of a donation presentation or updates from a SNOD. A SNOD explained that they had arranged for

a recipient to give a talk “to ICU staff and there wasn't a dry eye in the house. And the majority of the consultants came in for it. That had a huge impact, I think.” A number of ICU consultants remarked that hearing from a person who has survived because of a transplanted organ is appreciated and illustrates how the challenging process of donation can “be worth it.” In keeping with these comments, a few SNODs and CLODs explained that feeding back communications between donor families and transplant recipients to ICU staff has also helped in raising awareness about the benefits some donor families experienced after their donation experience upon the passing of their family member.

It is important to note that while many staff members pinned their positive view of donation in part to the benefit it could potentially create in the life of a transplant recipient, most were equally careful to explain that “transplantation needs aren't the motivation to facilitate donation.” As one ICU staff member elucidated, “[m]y patient is the one in the ICU bed – not a patient elsewhere needing an organ.” In a number of interviews and focus groups, staff explained that “things [success of donation or transplantation] can miss the mark – timing, post-op, etc”. Therefore, in light of the uncertainty of donation success, many staff were clear that their focus in a donation process was on patient care and choice, and supporting patient families.

### 1c. Staff feel that implementing an opt-out system could have positive impacts

In the majority of interviews and focus groups and across all staff role types, people anticipated positive impacts due to the change in law and implementation of an opt-out system in Scotland. They discussed various impacts a publicity campaign about the law change might have in raising the profile of donation, as well as anticipated increases in registrations on the Organ Donation Register. In line with themes identified in NHS staff members' positive views on donation more generally, their views on the positive impacts of moving to an opt-out system centred on patient and patient family care, as well as supporting patient choice. The following sections detail facets of staff views regarding the potential positive impacts of an implementation of an opt-out system.

#### Publicity can raise the profile of donation generally, and tissue donation specifically

NHS staff members hoped that the publicity campaign will instigate greater public understanding and awareness of donation, thereby creating a ‘culture shift’ around donation wherein families have conversations about their donation wishes; expect

donation to be discussed at the end of life; raise the topic with NHS staff themselves; and increasingly view donation as 'default' or 'normalised' end-of-life care choice.

ICU consultants' and nurses' hopes were grounded in wishing to reduce patient family stress during the difficult experience of having a family member in the ICU, particularly when that family member will not survive. Both ICU and ED consultants hoped that a publicity campaign would lead to more families speaking about organ and tissue donation and their donation wishes before "ever arriving to the ICU" or the Emergency Department. For example, an ICU consultant explained:

"I still feel slightly sad, the number of relatives I speak to...do you know what your relative's wishes were? And they say, no, no idea. And I think it's a conversation that everybody should be having with his or her family, so this is my wish. Because then if something ever does happen in that situation, when you say, do you know what your relative's wishes were? The answer is absolutely, I do." (ICU consultant)

An ICU nurse also explained the positive effect previous discussions within a family can have on the end-of-life experience of families when explaining their hope for a greater incidence of these conversations:

"And it's actually quite remarkable how some families have considered it before and it is really easy when they have and they are informed, it is effortless because...it is what they're thinking about already. They realise what's going on. And it's remarkable." (ICU nurse)

These comments show that staff positioned these prior discussions as reducing the "the surprise" for families when the topic of donation is raised during an end-of-life conversation. Numerous staff, particularly ICU consultants, had anecdotes from the ICU and ED about the emotional turmoil this uncertainty about a patient's wishes could create for families, as well as the stress staff themselves felt when families were in distress over this decision. Staff also linked this uncertainty to lower donation authorisation rates:

"[Y]ou get a group of patient families who will say, 'well I just don't know, I don't know what they [the patient] would want!' and they're paralyzed by not knowing. And I think when you don't know, people would rather do nothing than do something, so they're the ones that don't consent." (ICU Consultant)

This remark underlines a number of NHS staff members' views that currently the 'default position' taken when a family is uncertain about a family member's donation wishes is to 'do nothing', i.e. decide to not authorise donation. Non-authorisation was explained to be the default choice by families and some staff members postulated that an opt-out donation authorisation system might impact what patient families consider to be the 'default choice' when there hadn't been previous discussion about a family member's donation wishes. ICU consultants and SNODs, in particular felt



that the new law and its potential to create a culture change around donation would “make it easier for families to say yes [to donation]” because while donation “hasn’t normalised yet” as a default choice greater publicity could raise the public’s positive views of donation and its impacts.

Due to difficulties that uncertainty about a patient’s wishes can raise, in about half of interviews and focus groups, staff members also expressed hope that greater publicity of donation might lead to more families raising the topic of donation themselves, before or during the event of an end-of-life conversation. These staff members tied this to anecdotal evidence about a growing trend of families asking about donation or expecting donation to be discussed as a matter of course if their family member’s health declines. All staff members who described this trend of families cast it as a positive effect of a growing ‘culture change’ around donation. One ICU consultant explained that:

“It [families raising the topic of donation] happens once or twice and it’s interesting when it does. Often it’s people who were on a donation register and the families know about it and in those situations, sometimes they do bring it up. And when they bring it up, it just makes the whole situation a hundred times easier than it would be. Because then it feels like you’re sort of helping them to achieve something that they and their relative wanted rather than just asking them for a favour...” (ICU consultant)

As illustrated by this remark, staff members not only saw more openness and family knowledge about donation as reducing overall distress, but as an opportunity to work together with families to support patient choice. This links to the earlier discussion about patient choice, which was cited by many NHS staff members as an integral and valued part of their practice.

## Raising the profile of tissue donation

A number of staff members, particularly TDCs and ED staff, described that there was far less awareness about the particulars of tissue donation as compared to organ donation among the public and other NHS staff members, particularly in ICU contexts. This is partly because in ICU settings tissue donation is often authorised alongside organ donation. This was described as also having to do with differences in how people conceived of organ donation versus tissue donation. For example, a TDC explained that:

“...a lot of people don’t know about tissue donation, even random people ask me about my job outside of work when I start talking to them. ‘I didn’t realise, I’ve just ticked yes to everything, but never really thought about exactly what I’m ticking yes to’ or a lot of people who say I put no to eyes and then when I explained to them they’re like, oh, wow. Why did I tick ‘no’ to eyes?” (TDC)

In addition, a CLOD described a general lack of awareness about tissue donation among ICU staff:

“I think you forget about tissue because tissue is seen as, well, organ is seen as very lifesaving and tissue is not seen as lifesaving, well, life improving, perhaps. And there's less urgency for tissue, and I don't often have any tissue conversation because I think my knowledge of tissue donation is very, very limited.” (CLOD)

However, in a focus group SNODs explained that when a referral is made to them for a potential donor and they discuss authorisation with a family, they consider tissue donation as a matter of course, even if “most people don't realise there is a bit of difference between the two” [in terms of arranging the logistics of donation facilitation].

The issue of the difference in infrastructure and capacity to carry out tissue donation as opposed to organ donation in Scotland arose in a number of conversations with staff. The logistical issues highlighted were that tissue donation outside Scotland's Central Belt is rare and often not possible to carry out. These staff members reflected on this difference in capacity as an impacting factor on the lower awareness of tissue donation, particularly in the northern regions of Scotland. In addition, some families have difficulty allowing their family member's body to be moved to a different location after organ donation to facilitate tissue retrieval.

NHS staff members that mentioned the imbalance in awareness and consideration of tissue donation, often then reflected on ways to rectify this imbalance. For example, a few interviewees mentioned the importance of raising awareness among ICU staff of that fact that while a patient may not appear to be a potential organ donor, they may be a potential tissue donor. Additionally, due to the high turnover rate of ED consultants, TDCs and ED consultants spoke about the need to continually train new ED staff coming into post about incorporating questions about tissue donation in their end of life conversations with patient families.

In line with this, an ED staff member suggested the use of different kinds of cueing tools to remind consultants in the ED to raise the question of donation in the event of death, as well as give suggestions on how to frame the conversation. Also, TCDs spoke about empowering ED nurses to speak to families who have just suffered the death of loved one:

“just to make the family aware that they have this option because when somebody signs up in their lifetime to be a donor, nothing flags up on the system in the hospital you know, the computers don't say that this is a potential donor. So we really rely on the hospital staff.” (TDC)

These reflections indicate that NHS staff members view the imbalance in awareness of and knowledge about tissue donation as something to be rectified.

## Publicity could prompt more registrations on the Organ Donor Register

Many staff members hoped that the publicity campaign associated with the new opt-out law would prompt more people to register their donation decision on the ODR. This was framed as a 'good' benefit of the law because it would allow more people to "actually think about it [their view on donation]" and create more instances in which patients' donation decision would be known at end-of-life. Further, many staff members commented that encouragement to register on the ODR should be coupled with direction to speak to family and friends about these wishes – both to prompt family conversation and more widely raise awareness of the ODR register. NHS staff views of the ODR as a tool link to NHS staff members' persistent attention to patient choice, as well as patient family care.

Comments made in most interviews and focus groups demonstrated that many staff members, and patient family members they have encountered, position a person's ODR status as an important indication of, or method by which, to "know", a patient's wishes. This conceptualisation of the ODR featured strongly in many discussions about what role the ODR would play in ICU and ED practice post implementation of the opt-out authorisation system, for a variety of reasons.

Firstly, many staff members explained that checking the ODR, or asking a SNOD to check the ODR, was an important element of considering whether a patient who will not survive might be a potential donor. Interestingly however, most ICU staff members said they always "called in the SNOD" or approached families regardless of whether a dying patient was registered as having opted in, opted out, or was not on the register. They explained that knowing a patient's ODR status helped them feel "more prepared" for an end-of-life conversation with family members when the topic of donation was likely to be raised, particularly if a SNOD was present during this conversation. ICU consultants in particular explained that a patient's "ODR status" (whether they have "signed up as a donor" or not) can be a helpful "way in" to a topic of donation in conversation. An ICU consultant explained that, "if they've already registered [on the ODR], it will just make the conversation even easier still. I think that's those are the easiest conversations." Another said:

"And what it then does is, what it will do is flag up a system that this person has opted out and it will mean at that point we know what their wishes were...So actually, we have to just to confirm to the relatives that that's still the case. But it's a clearer starting point to begin with." (ICU consultant)

While this view was the norm, it is important to note that a few ICU consultants explained that if a patient had opted *out* on the ODR, they were less likely to consider a patient as a potential donor or donation as an appropriate topic for discussion with family to check that their loved one's latest view was that they did not want to donate.

Additionally, the majority of ICU consultants spoke about the significant role a patient's ODR status can have in conversations with family members, particularly when the topic of donation had not been discussed within families previously. A SNOD explained that "some families don't know their loved ones are on the register so it is a surprise when they are told." They highlighted that a patient's ODR status can significantly impact a family's decision to authorise donation, reduce emotional burden on families related to donation uncertainty at their family member's end-of-life, and allow NHS staff to place them in a position of facilitating a patient and/or families wishes in regards to donation. As one ICU consultant explained:

"I think it takes a lot of pressure off relatives in that situation where actually they know their relatives wishes and they don't feel like they are having to make that decision on behalf of the relatives. They can act as more of an advocate for their relatives wishes rather than feeling that the decision falls on them to make." (ICU consultant)

The views outlined in this section illustrate that many staff felt that higher ODR registrations would lead to easier, more straight-forward conversations with families, again underlining the importance NHS staff place on patient family wellbeing.

It is important to note that the ODR was discussed less often by the staff interviewed who work within ED settings. ED Consultants explained that because end-of-life circumstances often occur more suddenly in ED settings and there is less time to discuss end-of-life care options, "checking the ODR" or speaking to families about donation is not standard practice. Further, an ED Consultant explained that a patient who is stabilised within an ED setting, but still in critical condition is then often moved to an ICU setting. Therefore, that patient's care, and end-of-life care, if they are unfortunately not able to survive, is conducted by ICU staff.

## 1d. Staff highlighted difficult aspects of the donation process

While NHS staff members on the whole are supportive of organ and tissue donation as a normalised option within end of life care, many staff members also outlined the ways in which donation can be a challenging and difficult process for staff members and families alike. As one ICU consultant explained:

"I am supportive of it [facilitation of donation] but I think it's a very complicated topic. And I think ethically, emotionally, I think it's one of the hardest things that we do in intensive care. I absolutely see the benefit of it at the other end but I think it is very complicated. I don't think it's a black and white transaction at all." (ICU consultant)

It is important to note that while this section details challenging aspects of the donation process, staff members also outlined a number of ways to build a positive

donation culture and successful donation processes, and meet the challenges inherent in donation, which can be found in section 2 of this report.

In interviews and focus groups, staff members' discussion of the challenging aspects of donation largely centred on the logistics of the donation process, particularly those related to determining potential donor/transplant recipient suitability and organising the donation procedure. Staff members, particularly ICU consultants highlighted that the complex logistics of these processes can result in long wait times, which is difficult for both families and ICU staff. For example:

"I think extensive delays and uncertainty...here they [patient families] have maybe already had a couple of days of disrupted sleep. You know, the family are struggling because they've been in the hospital, had this bedside vigil for someone they hoped was going to survive and then isn't now going to survive. And then to prolong that further by, you know, 24 hours, often or longer, it's sometimes just too much. Yes. It's system problems, but it can also sometimes just be [too much for] the family themselves." (ICU consultant)

Often, when this concern about the challenges of donation was raised, staff then linked it to earlier discussion of their focus on patient and patient family care, demonstrating that the main challenges of a donation process are seen as those which could potentially create a difficult experience for families.

One suggestion that came out of a few focus group discussions among ICU staff was the potential for more communication between the ICU team and families during the donation process, to mitigate uncomfortable uncertainty about the reason behind long waits and help families to feel included after they have given authorisation for donation. ICU staff in particular also felt that a post-donation audit from the NHSBT, giving a rationale for the wait times, would help them better understand how the process works, so they could, in turn, explain it to families.

A small number of staff members also raised the issue of bed space, which can create difficult decisions for ICU consultants. Some see using an ICU bed to facilitate donation as appropriate, whereas others do not. In interviews, those that expressed support for using an available ICU bed to facilitate a potential donation tied this to the duty to support patient and family choices about end of life care. Only a small number of interviewees did not support this and they linked their hesitation to concerns about how emerging ICU bed space and personnel demands would be complicated by a recently admitted patient that is past the point of life-saving care.

Finally, several staff members voiced concerns that members of the public lack understanding about what organ donation entails in an ICU setting, as it can be a prolonged and emotionally exhausting experience for patient families. In line with this, a handful of consultants shared the view that because of this lack of public

understanding of the challenges of an organ donation process, an opt-in decision registered on the Organ Donor Register may not have been made with 'full informed consent'. Two consultants felt that opportunities to learn about how to register on the ODR registrations made in conjunction with other services, such as when registering "for a Boots card" can create situations in which a person's registration was not "an active decision."

## 1e. NHS staff members are invested in a sensitive move to opt-out

When asked about any concerns that they might have about moving to an opt-out authorisation system, the majority of staff responded with some concerns. Most of these centred on wanting to ensure that patient and patient family trust was maintained in a move to an out-opt system. Other concerns, named by a few staff members, were that donation might not be seen as a 'gift' in an opt-out system, and that implementing an opt-out system might not achieve the intended goal of increased donation rates.

### The importance of maintaining patient and patient family trust

Many staff felt that the tenets of the current donation system that instil patient family trust would be maintained in the new system. When discussing concerns about losing trust, many NHS staff explained that it was paramount that patients and families understood that donation is only considered *after* all clinical care options have been considered and determined to be futile, both in the current donation system as well as after the opt-out authorisation system is implemented. To illustrate this point, an ICU consultant explained:

"...families have got to understand and believe us that we have tried everything that we possibly can within the realms of possibility of medicine that's appropriate...And if they don't trust that, they won't trust you and they'll go away...they'll go away in distress that they've been misled, so first of all, [you have to] make sure that you've achieved the goal [of speaking to families about the patient's inability to recover] first before you bring up organ donation. And they have to understand that this is inevitable. Death is inevitable. There's no other options here. And what's more, this doctor has been absolutely dedicated with no external biases whatsoever to making sure that every stone was turned in looking for a solution to make this precious person survive." (ICU consultant)

A smaller subgroup of staff members who spoke about the importance of maintaining family trust, particularly ICU consultants, also brought up the topic of SNODs. These

staff members indicated that the inclusion of a SNOD in end-of-life conversations with families could be a potential challenge in maintaining family trust in the current donation system and in the move to an opt-out system. These ICU consultants explained that because the SNOD is a staff member dedicated to donation work and in many cases has not met the family prior to an end-of-life conversation, they worried that families might interpret the SNOD's inclusion in end-of-life conversations as 'lacking intimacy' and 'too fast' if they need to first process the fact that their family member will not survive, before considering donation.

These particular ICU consultants who expressed discomfort with including SNODs in end-of-life conversations highlighted that they preferred to keep end-of-life conversations and donation conversations separate so as to protect the role of ICU staff as providing care to the patient. A number of ICU consultants also expressed discomfort at including a SNOD in an end-of-life conversation and/or introducing a SNOD as an 'end of life nurse' or 'palliative care nurse' because this felt dishonest and risked patient family trust. This was raised as a particular concern with families who 'don't see the end-of-life conversation coming'. As such, staff members, particularly ICU consultants and SNODs suggested that their role be disclosed to families carefully, so as to position SNODs as a resource to answer queries about donation, but "not presume that donation will be the next step." This topic is also included in section 2c.

It should be noted that a large number of staff members commented that including the SNOD in end-of-life conversations with families has had a positive impact on families' experiences, "particularly among the families that saw it [an end-of-life conversation] coming and ask questions about donation straight off."

### Some staff had concerns deemed authorisation could diminish the 'gift' of donation

A small number of staff questioned whether a 'deemed' authorisation system might diminish the idea that organ and tissue donation is a voluntary 'gift', and instead create an expectation for patients and patient families to authorise donation, or as one ICU consultant explained, "people [might] feel they are being pushed into something." Staff that raised this concern highlighted their desire to protect patient families from "unnecessary stressful experiences" that might arise if families felt that their family member's clinical staff expected them to move forward with donation, or alternatively, if families felt that their views or input in the authorisation process was not necessary as it an opt-out system were based purely on a patient's donation decision. As such, staff saw that their delivery of the donation discussion/question would need to be carefully delivered to make it clear that donation "isn't mandatory – it's a choice", and still give family their 'role' in allowing donation, but situate it as allowing the NHS to carry out a patient's wishes. This approach was described by staff members that expressed worries about the diminishment of the 'gift', as well as

also by those that did not raise this concern. When describing this approach, staff often linked it to the importance of honouring a patient's wishes as well as caring for patient families.

## Some staff had concerns opt out might negatively impact donation numbers

While the majority of staff members saw the move to an opt-out authorisation system as likely to have a positive impact on donation authorisation rates and see deemed authorisation as in line with current practice, a small number of staff members expressed concerns that a move to this system might negatively impact authorisation rates. This concern was linked to a few different potential issues. One issue raised by a few staff members related to the 'donation as gift' concern described in the previous section; some staff worried that if families felt pressured to fulfil an expectation of donation, they might react in the opposite way.

Several staff members worried that an influx of people might register an opt-out donation decision on the ODR, making them 'unreachable' as potential donors because conversations about donation as an option in the event of an end-of-life conversation would no longer be deemed appropriate. In line with this worry, staff also hypothesized that because under an opt-out donation system, one's decision to donate is 'deemed', people might not feel it necessary to still register an 'opt-in' decision on the ODR, creating fewer instances in patient's have a registered pro-donation decision. An ICU consultant expressed this concern that with fewer opt-ins, "you [could] have a whole lot of people that nobody knows what they want anymore." Another ICU consultant explained:

"I don't know how it will work out in practice...if somebody has really opted in I suppose you can say to the family this person is really opted in, they wanted their organs donated and there might be a little bit more willingness on the family side to say, OK, I'll go with that, they clearly opted in and that's what they wanted. Although some families will still say no. Who knows. It also could be that family might be like, well, we're not sure and we don't know if that's what they wanted considering they didn't opt in, at least they didn't opt out. I don't know. I don't know if that's going to be more hesitation on the family side or not. So, yeah, I'm not sure how that's going to pan out in actual practice but in principle just the idea of creating a bigger pool of people that are potential organ donors. I think it's a good principle." (ICU consultant)

The participants' comments demonstrate that a registered decision in the ODR supports staff to have this conversation and can help families to feel more secure in authorising a donation or balancing their own views about donation with those registered by a patient. This underscores the link between an ODR decision and family decision making, also discussed in sections 1b and 1c.



## Section 2: Supporting successful authorisation processes

This section relates to research question 3:

How can successful early identification and referral of potential donors, and successful authorisation processes best be supported? What supports a reduction in missed donation opportunities? What are barriers to the successful realisation of these aims?

### Key Findings:

NHS staff identified a number of ways to uphold a growing trend of donation support within NHS units in light of a move to an opt-out system:

- Greater visibility of SNODS and CLODs in clinical settings can raise the profile of donation.
- Good relationships between a SNOD and clinical staff supported successful authorisation processes.
- Careful inclusion of SNODs in end-of-life conversations can maintain patient family trust.
- Increased and earlier education about donation could be beneficial in normalising donation as part of end-of-life care in ICU and ED settings.
- Positive feedback from NHSBT and experience of being a part of a 'successful donation' process can buoy confidence and understanding.

These measures were identified within a context that many interviewees described as a growing awareness of, and support for, organ and tissue donation within NHS units in the past decade, and linked this to increasing donation authorisation rates. They often linked this trend with frequent discussion about donation as a consideration in a patient's end of life care, high referral rates of potential donors to SNODs, and authorisation discussions with families that promoted patient choice, but also supported families' wellbeing. The vast majority of staff members identified these elements as hallmarks of a successful unit who worked to minimise the number of missed opportunities for donation to be considered for patient who has been assessed as unable to survive.

The measures identified by NHS staff are detailed below and presented in order of prominence in discussions.

## 2a. Greater visibility of SNODS and CLODs in clinical settings

Many staff members, particularly ICU nurses and consultants, explained that the 'visibility' of SNODs and CLODs in their units made a difference in promoting a donation-positive work culture, feeling confident in best practices regarding donation process, and that donation was expected to be considered or offered as an end-of-life care option.

Many staff members explained that 'embedded SNODs', i.e. those that work within (or are stationed within) a particular unit, are assets to a successful donation system. ICU consultants in particular explained that 'having a SNOD right there [in the unit]' allows for more accessibility for 'quick questions that [staff] might not otherwise pick up the phone for' and facilitates the development of good rapport between SNODs and ICU staff. Staff also explained that 'embedded SNODs' also allows for more frequent, casual referral, and discussion of potential donors, which many staff found more in keeping with the intimacy of patient care than "calling it in [checking the ODR or speaking with a SNOD] before we've spoken with the family."

In line with visible SNODs, many ICU staff also mentioned that having "an active CLOD" helped to set a positive, motivated tone of donation culture within the unit and served to create a source of donation expertise within the unit. In hospitals that did not have 'embedded SNODs', staff members described that the role of donation experts that CLODs held, allowed them to field casual questions in ways similar to SNODs. Some also described CLODs as "the friendly face to the NHSBT missed opportunity/referral audit."

## 2b. Good relationships between SNODs and clinical staff

Many NHS staff explained that a 'good' relationship between a SNOD and the clinical staff who are in charge of patients and who speak with patient families can support a successful authorisation system. This point was raised by consultants, nurses, and SNODs. Staff linked a good relationship and frequent, informal 'chats' with SNODs with decreased missed opportunities for referral to a SNOD as well as increased familiarity with the donation eligibility criteria. Staff working in ICU settings with an 'embedded SNOD', a SNOD who primarily operated out of that setting, described this set-up as ideal for "asking the quick question." A few members of staff that do not have an 'embedded SNOD' said that they had a good relationship with the SNODs that most frequently attended their site in the event of a potential donation, but "could see the benefit and convenience" of having an embedded SNOD in asking more informal questions about the process outside periods when a donation process was underway and time might be more constrained.

Consultants were asked about the hallmarks of a good relationship with SNODs. A number felt that it was important when SNODs appreciated the rapport that they (the consultants) had built with families. A few said that when SNODs do not appreciate this rapport, they feel reticent about the SNOD working with the family in case the family's needs are not considered. One consultant explained:

“I think we are in quite a unique position in the intensive care team in that we've looked after this person and you've spoken to the families a lot, we've got to know the dynamics within the family, dynamics with the patient...I think it would be wrong to suggest that we do not have an insight as to where the family are emotionally and how they are coping with things. And different families definitely cope in different ways and reach their sort of threshold for being overwhelmed at different points. And I think we have quite a unique privileged position of understanding that because of the fact that we've looked after them for a period of time before it gets to this stage where futility<sup>5</sup> has been reached and you're discussing organ donation.” (ICU Consultant)

SNODs raised the topic of rapport in focus groups as well. Many SNODs described that it was important to build their consultant colleagues' trust in them to work with patient families compassionately. As explained one SNOD explained:

“having a side chat with the consultant – and the nurse too, maybe, before you speak with the family is really important. It helps you understand where you are – where the family is at, so you can approach them in the best way possible.” (SNOD)

SNODs who expressed this view linked these 'side chats' with having established a good relationship with the consultants with whom they work.

## 2c. Clarifying SNODs' role at end-of-life conversations

Some staff perceived pressure to have a SNOD present for end of life conversations with families, a topic also discussed in section 1e. In a number of discussions, some ICU consultants highlighted wanting to keep conversations about end of life and conversations about donation separate from one another. Those that expressed this view explained that separating these conversations can protect the family's understanding that the role of ICU staff is to provide care to the patient. A number of ICU consultants also expressed discomfort at including a SNOD in an end-of-life

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<sup>5</sup> Futility in this context refers the clinical determination that a patient is not expected to survive and no further treatment options are appropriate or would change the patient's prognosis. Only when the clinical team have discussed and agreed with the patient family that nothing more can be done, will a sensitive discussion start to take place about the possibility of donation.

conversation with patient families or a introducing a SNOD as an ‘end of life nurse’ or ‘palliative care nurse’ because this might risk patient family trust.

## 2d. Increased and earlier education about donation

Across ICU and ED settings, and across staff group types, a small number of interviewees recommended an increase in education about donation, and incorporating education about donation earlier in clinical staff’s training. It was explained that earlier education can normalise the consideration of donation within both ICU and ED settings, and would not create situations in which staff need to learn ‘everything about it on the job’, as one ICU consultant put it.

## 2e. Positive feedback and experience can buoy confidence and understanding

In interviews and focus groups, some staff members expressed that feedback from NHSBT<sup>6</sup> about operations or audits can sometimes have a ‘reprimanding’ tone, which they found demoralising. One ICU consultant explained that feedback did not capture the nuanced and valid reasons behind particular decisions made or events that occurred in a donation process, such as why a family was not approached about donation, which is then recorded as a ‘missed opportunity’ in the audit.

In contrast, a larger number of staff members, particularly ICU consultants, explained that reports back about successful donation processes, such as information about subsequent transplants from previous patients in their ward, were very uplifting for the ward team as a whole. A large number of ICU consultants and CLODs mentioned how important information about this was, or could be, for keeping up support for donation, “showing that all the effort is worth it”, and “feeling like the families who had a rough time found solace” from the process as well. For example:

“There's no feedback. And I think that we are, certainly this unit and I'm sure most other ICUs are driven by making sure that our patients and family members get the best care possible. And I think if we were able to see that organ donation was the best cure for these patients, for these families, that it helped them with the grieving process, then I think that would probably be the most persuasive argument we could make.” (CLOD)

A few described this approach as one built on a positive reinforcement model, in which success was compounded with discussion about what had made a team or process successful, and drawing out learning from these examples. A small number

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<sup>6</sup> NHS Blood and Transplant coordinate transplantation on a UK basis on behalf of the four nations, and routinely provides feedback to ICU departments and staff about that department’s activity related to donation, such as missed opportunities, authorisation numbers, successful donation and transplantation activity, etc.

of these staff members also mentioned that reports on tissue donation successes could be important in raising the profile of tissue donation in ICU contexts.

The topic of 'success stories' arose in a few different focus groups and interviews with SNODs. It was suggested that letters from transplant patients or donor families could provide ICU units with evidence of the positive outcomes of their efforts to make a donation possible.

## Section 3: Reflections on how NHS Staff Training can support a successful move to an opt-out system

This section relates to research question 4:

What are key areas that training should target to raise awareness and knowledge of, and support for tissue and organ donation, and opt-out authorisation among NHS staff?

### **Key Findings:**

NHS staff members were asked to reflect on the implementation activities that will be rolled out in preparation for the new law, namely training and awareness raising sessions aimed at staff. In general, across the different staff groups, key issues centred on wanting:

- Clarification on legal stipulations of the move to an opt-out authorisation system and how it would affect their practice.
- Clarification on issues regarding communication with SNODs/TDCs, other ICU units, and with ED staff.

In general, staff felt confident that this would be covered in the training/sessions organised by Scottish Government and the NHSBT.

The key areas staff hoped would be addressed in these sessions, are detailed below and organised according to NHS staff role type.

### 3a. Views of SNODs and TDCs

Views among SNODs and TDCs centred on viewing training as a necessary opportunity to gain clarity and better understanding of legal stipulation of the change to a deemed authorisation system, and how to ensure “all the new rules are followed.”

The key items identified as important to address training/events were:

- SNODs and TDCs hoped for greater clarification on any changes that will be made to the authorisation form.
- SNODs and TDCs also hoped for greater clarification on the legal stipulations of ‘deemed authorisation’, wherein a patient has opted into donation on the ODR and/or clearly stated a wish to donation, however families do not wish to proceed with donation – or a vice versa situation. SNODs particularly sought

this clarification so as to be prepared to explain best practice in these complex situations to consultant and nursing colleagues.

- This group also suggested that discussion of different kinds of scenarios in which ‘duty to inquire’ is pursued would be useful, so as to build their confidence with ‘putting it into practice’ with families.
- Discussion of best practices for Specialist Requester/SNOD teamwork was also requested, so that speaking with families and organising tests to assess the potentiality of a donor progresses efficiently and ensures patient family support.
- This group also sought clarification on pre-death procedures: what changes will be made to current procedure lists, and when these changes will be made official.

### 3b. Views of CLODs and ICU/ED consultants

Views among ICU consultants covered a wider spectrum than for other staff groups, with some consultants not viewing training as particularly necessary and others seeing them as an important opportunity to get clarity and better understanding of the organ/tissue donation in general.

The key items to address that were identified by those positively anticipating training/events were:

- Clarification of the legal stipulation of ‘deemed authorisation’: akin to the clarification sought by SNODs (as described above). Many CLODs and consultants mentioned wanting to have a more confident understanding of what “deemed authorisation actually means in practice”. CLODs recounted more confidence with this concept than consultants did, with more consultants wondering whether they “would have to move forward with donation if someone’s on the register despite what families say”.
- Many expressed curiosity about the public marketing campaign to support the implementation of the opt-out system. They were specifically interested in learning about the public messages about the importance of registering donation wishes on the ODR, and how the marketing campaign might impact knowledge about “what donation entails” and “deemed authorisation” among their future patients/patient families.<sup>7</sup>

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<sup>7</sup> It should be noted that interviews were conducted prior to much of the public awareness activities implemented to support raised awareness about the law change among the public.

- Consultants, in particular ICU consultants, were interested in ways in which more communication between ICUs could be supported so that 'best practices' and 'problem solving' techniques regarding donation developed within different health boards/other sites could be shared across different teams.
- Many suggested that signposting that 'SNODs are the experts – it's best to always refer to them when in doubt' alongside case studies. In line with this, a number of consultants requested clarification on research showing that SNODs 'in the room' during end-of-life conversations correlates with higher authorisation rates as a few mentioned conflicting evidence on this finding.
- This group also hoped for training/sessions to create great clarity on 'duty to inquire' stipulations; staff expressed varying levels of confidence in their understanding of what this practice entailed and how it would affect families in practice. Some staff suggested the inclusion of different 'duty to inquire' scenarios to remain confident that potential donor and donor families' wishes would be taken into account in authorisation conversations, and that trust in the ICU/NHS would not be hurt by deemed authorisation conversations.
- ED consultants and nurses also highlighted the need for greater awareness raising of tissue donation among ED staff, with 'clear, simple guidelines how to speak with families' of the recently deceased so that ED staff's confidence in raising this topic is raised and encouraged.



## Bibliography

Erlingsson and Brysiewicz 2017. A hands-on guide to doing content analysis. *African journal of emergency medicine*, (7: 3).

Evanisko et al. 1998; Readiness of critical care physicians and nurses to handle requests for organ donation, *American Journal of Critical Care*, 7 (1)

Garcia et al. 2008; Educational program of organ donation and transplantation at medical school. *Transplant Proc.*, 40(4)

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.

Muthny et al. 2006, Training for Doctors and Nurses to Deal With Bereaved Relatives After a Sudden Death: Evaluation of the European Donor Hospital Education Programme (EDHEP) in Germany, *Transplantation Proceedings*, (38)9.

Organ Donation Taskforce, 2008. *The potential impact of an opt out system for organ donation in the UK*.

Rithalia, A. et al., 2009. A systematic review of presumed consent systems for deceased organ donation. *Health Technology Assessment* , 12(26).

Roels et al 2010. Critical Care staffs' attitudes, confidence levels and educational needs correlate with countries' donation rates: data from the Donor Action database. *Transpl Int*, 23(8)

Willis, B. a. Q. M., 2014. Opt-out organ donation: on evidence and public policy. 107(2).

Simpkin et al 2009. Modifiable factors influencing relatives' decision to offer organ donation: *systematic review BMJ* 2009.

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).

Symvoulakis, E, 2014. rgan Donation Knowledge and Attitudes among Health Science Students in Greece: Emerging Interprofessional Needs.. *International journal of medical sciences*, Volume 10.

Pelleriaux, B. et al., 2008. An analysis of critical care staff's attitudes to donation in a country with presumed-consent legislation. *Prog Transplant*.

## Annex

### **A. Data Analysis: Content Analysis Approach**

In brief, the process of content analysis began with a review of the whole of transcription data to gain a general understanding of the whole of the data content, which was then divided into smaller parts, or 'meaning units' which indicate concise ideas, actions, impacts, attitudes, context etc. These meaning units were then coded with descriptive labels based on themes that emerge from a review of all the 'meaning units'. Connections between different codes were identified. Based on these connections, codes were then organised into larger categories, under which codes will pertain to the same issue fall. Categories can be further abstracted into themes. This method of analysis was used because it allows for both broad and specific findings to emerge through the analytic comparison at the coding, categorisation, and thematic grouping stage. Categories and themes were cross-referenced, which was important for this multisite project as nuanced differences arose within one theme/category from site to site. This analytical approach also protects against distortion and bias, as themes and codes are identified in consideration of all data collected, and therefore do not privilege any particular subgroup of participants. Finally, it allows for a close consideration of meaning units or codes which run across multiple themes, or fall outside the broader category and theme groupings, or are less closely related to the research questions.

### **B. Literature Review**

Research on organ and tissue donation systems outside Scotland shows that alongside a transition to an opt-out authorisation system, infrastructure improvements appear to be important factors in contributing to increased organ donation and transplant rates. For example, Spain has one of the highest rates of organ donation in the world, which began to rise a decade after the implementation of an opt out authorisation system with the concurrent establishment of new infrastructure (Organ Donation Taskforce, 2008). Further evidence supporting the importance of infrastructure is illustrated by an examination of particular regions of Italy which found that these regions' organ donation rates doubled after adopting an infrastructure model similar to the Spanish infrastructure (Willis, 2014). Additionally, an evaluation of the Austrian organ and tissue opt-out system claims that Austria's largest increase in organ donation was driven by infrastructure changes, such as the use of full-time transplant coordinators (Rithalia et al., 2009).

Research has also found that medical staff play a particularly prominent role in increasing organ donation rates (Glasper, 2018). Research shows correlations between staff knowledge about, and attitudes toward organ donation, and organ and tissue donation rates within their country (Roels et al., 2010). Currently, no data exists with regards to these themes within the Scottish context. Data does however exist on these themes within the Welsh, and other international contexts. The Welsh Government commissioned a survey to explore the attitudes and awareness of NHS staff in Wales due to the transition to an opt-out authorisation system for donation (The

Welsh Government, 2017). This evaluation was conducted pre and post implementation and examined the views of a wide range of NHS staff, not only those staff involved in donation, (which is the target group of this application). The Welsh evaluation found that 71% of NHS staff in Wales supported the change to opt-out before implementation of the legislation, which increased to 89% post implementation. In addition, staff awareness of this change was fairly high before implementation (89%) and increased to 96% post implementation. Several key findings from the Welsh impact evaluation highlighted how staff could be supported during opt-out infrastructure changes. It stressed the importance of ensuring that NHS staff have a clear and robust understanding and knowledge of the new donation opt out authorisation system, and highlighted that NHS staff benefited from further training which centred on themes such as skills in approaching the donation conversation with potential donor families, which is most pertinent for relevant for staff working in critical care areas.

International evidence also supports findings 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, alongside knowledge of donation processes, is important in effectively communicating with families about the organ donation process and may lead to higher authorisation rates (Pelleriaux et al., 2008). Further, a Greek evaluation indicated that staff education for health service staff is key to gaining support for a change to an opt-out authorisation system within the public sector and increasing organ donation (Symvoulakis 2014). Similar research in Hungary tracked staff attitudes to, and knowledge of donation in an examination of medical staff training, concluding 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). These findings corroborated earlier research on the important links between staff training, staff attitudes, family communication, and donation rates (Evanisko et al. 1998; Garcia et al. 2008; Muthny et al. 2006; Simpkin et al 2009). The international evidence demonstrates that staff support in form of knowledge and skills training for organ and tissue donation processes is more likely to achieve 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 an opt-out authorisation system for organ and tissue donation.

In summary, these bodies of research demonstrate the importance of infrastructure changes alongside donation opt-out across various European contexts in improving donation rates. They also show that the attitudes and knowledge of medical professionals play an important role in increasing donation rates. The findings from this body of research also demonstrate the importance of training shifting NHS staff's attitudes toward, and knowledge of, donation processes, and that training can lead to improvements in overall donation rates. These findings demonstrate the importance of understanding the current donation process, specifically referral and authorisation processes, and infrastructure within Scotland, and knowledge and views of organ and tissue donation held by NHS staff members.

For further information, please refer to the June 2018 Scottish Government publication: [Opt out organ donation: a rapid evidence review - gov.scot \(www.gov.scot\)](http://www.gov.scot/Topics/Health/Transplantation/organ-donation)

## **C. Interview Topic Guide, as submitted as part of the Evaluation's NHS RINTAG application**

### Qualitative Interview Topic Guide

Questions guiding the Baseline Service Evaluation:

- What are NHS staff members' views on, understanding and awareness of the new opt-out authorisation system?
- What are NHS staff's views on the NHS organ and tissue donation system, and donation as part of end-of-life care?
- How can successful early identification and referral of potential donors, and successful authorisation processes best be supported? What supports a reduction in missed donation opportunities? What are barriers to the successful realisation of these aims?
- What are key areas that trainings should target to raise awareness and knowledge of, and support for tissue and organ donation, and opt-out authorisation among NHS staff?

### Interview Questions Topic Guide

A. Introduction, overview of study, consenting:

- Thank you for seeing me today and offering to take part in this study.
- I would like first to outline the study so that you are able to decide whether you wish to proceed further (recap information sheet).
- Sign consent form × 2 (one for participant and information sheet, one for interviewer).
- (Topic List) I have a list of topics that I want to address, which will pertain to your perspectives on donation, donation processes, the change to an opt-out authorization system, and NHS staff trainings relating to this.
- Feel free to ask questions at any stage during the interview.
- I might make a few notes in case I want to come back to something later.
- Need to make sure it's clear that your personal information will be kept confidential, only viewed by myself, and that data will be de-identified to 4 geographical regions, and NHS role.

B. Interview Discussion:

## Topics/questions

1. Background information on the interviewee.
  - Current and any prior relevant roles/responsibilities, training, duration in employment.
2. Views on, understanding and awareness of the new opt-out authorisation system
  - What is your understanding of the new legislation, that will change donation authorisation from opt-in to opt-out?
3. Views on, and attitudes toward organ and tissue donation/donation system
  - What are your views on donation and the current donation system?
4. Trainings
  - What do think works about the donation process well? What doesn't?
  - What supports successful authorisation processes?
  - What supports a reduction in missed donation opportunities?
  - What are barriers to these?
  - What do think should be targeted in NHS staff trainings to make a change to opt-out authorisation system a success? To support overall donation rates?



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