

POTENTIAL DONOR AUDIT FEASIBILITY STUDY REPORT



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**With the assistance of the Potential Donor Audit
Feasibility Study Steering Committee**

NATIONAL OFFICE OF CLINICAL AUDIT (NOCA)

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The National Clinical Effectiveness Committee (NCEC) defines national clinical audit as “a cyclical process that aims to improve patient care and outcomes by systematic, structured review and evaluation of clinical care against explicit clinical standards on a national basis” (NCEC, 2015, p. 2).

NOCA supports hospitals to learn from their audit cycles.

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Potential Donor Audit Feasibility Study Report

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31 January, 2022

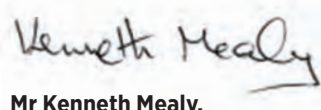
Dear Dr Gaffney,

I wish to acknowledge receipt of the *Potential Donor Audit Feasibility Study report*.

Following your presentation to the NOCA Governance Board on the 27th January 2022 and feedback garnered from our membership, we are delighted to endorse this report. I wish to congratulate you, Maria Kehoe, Postdoctoral Researcher and the Steering Committee in the development of this report.

Please accept this as formal endorsement from the NOCA Governance Board of the Potential Donor Audit Feasibility Study and we wish you every success in your ongoing commitment to the organ donation transplant service..

Yours sincerely,



Mr Kenneth Mealy,
Chair
National Office of Clinical Audit Governance Board

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FOREWORD

“If you cannot measure it, you cannot improve it.”

Lord Kelvin

Organ transplantation is one of the most fascinating advances in modern medicine; a therapy that transforms the lives of more than 150,000 patients across the world every year. But the unique feature of transplantation compared with other types of health interventions is its reliance on the availability of an organ altruistically donated by a person during their lifetime or after death. Though 28,212 transplants were performed in the EU-28 in 2020, this activity covered 27% of patients active on the waiting list for that entire year. In 2020, some 11 patients died each day in the European Union (EU) while awaiting an organ. The disparity between supply and demand of organs for transplantation is expected to keep growing in the coming years as a result of the progressive ageing of the population and the increasing burden of diseases that can lead to end-stage organ failure. The World Health Organization has called on governments and healthcare professionals to pursue self-sufficiency in transplantation and, in order to increase the availability of organs, to develop deceased donation to its maximum therapeutic potential. This raises two immediate questions: What is the potential of deceased donation? And how do we measure it?

Often those who intend to improve deceased donation rates in a given jurisdiction think of *magic bullets* – as promotional campaigns or reforming the existing legislation towards an opt-out system – with the expectation of an immediate increase in the availability of organs. These measures have never proven to result in sustained improvements in organ donation. Besides, they depart from the fundamental error in believing that if organ donation does not work in a given setting, it is because of the people. In the words of Rafael Matesanz, the previous director of the Spanish Organización Nacional de Trasplantes, we should “never blame the population; if people donate less, it must be something we have done wrong”.

With time, organ donation and transplantation systems throughout the world have understood that the key to success is the exquisite management of a multidisciplinary process of high complexity – the deceased donation pathway. A managerial approach that ensures the systematic identification of those exceptional circumstances of death that are consistent with organ donation and the smooth transition of possible into utilised organ donors is precisely what can transform the reality of deceased donation in any setting. This means appointing the right professionals, providing them with appropriate guidance and continuous training, and assessing performance. And this is precisely where a Potential Donor Audit (PDA) fits. Without data, without precise data, we cannot succeed.

A PDA offers valuable information that we, as managers of donation programmes either at a national, regional or hospital level, need to assess and monitor trends in the potential of organ donation. Is the potential for donation changing? Is the profile of potential donors becoming different with time? Data collection is also critical to identify opportunities for improvement. Are we failing to identify potential donors? Are medical contraindications that lead to potential donor losses appropriately established? Are we ensuring adequate donor management? A PDA is essential for benchmarking, i.e. for identifying those hospitals and units with excellent performance, to learn of good practices that can be transferred to other centres. Data collection is, in addition, an essential tool for research in organ donation – which in turn transforms our field in a critical area of knowledge, and thus more attractive for healthcare professionals involved. There is a long list of benefits associated with a PDA that makes this type of programme essential.

After reading this report commissioned by Organ Donation Transplant Ireland and conducted by the National Office of Clinical Audit, I can only congratulate the Irish leaders for this initiative. The report offers a comprehensive overview of some of the existing PDA programmes in the

world, and of ongoing data collections of potential relevance to organ donation in Ireland. It concludes with the need for developing and sustaining a PDA adapted to the Irish reality. But, most importantly, the report reflects a commitment to continue improving deceased donation activities in the country. It shows the determination of providing professionals in this setting with a fundamental tool to finally improve access for patients to the organ transplant they need and to offer more patients (and their families) the opportunity of donating organs if this is consistent with their principles and values. It will take time and effort to count on a refined and truly useful mechanism. But whatever the time and effort this takes, it will be worth it.

Beatriz Domínguez-Gil
Director General
Organización Nacional de Trasplantes, Spain

EXECUTIVE SUMMARY

Organ donation saves lives and improves the quality of life for people with end-stage organ failure. It involves the selflessness and compassion of organ donors and their families supported by dedicated frontline organ donation personnel (ODP) and Organ Donation Transplant Ireland (ODTI). Out of 72 countries worldwide, Ireland ranks 28th in terms of organ donation rates (Global Observatory on Donation and Transplantation, 2021). Rates of organ donation are 18 per million population (pmp) in Ireland compared to 25 pmp in the United Kingdom (UK) and in excess of 45 pmp in Spain. Rates and ranking of organ donation rates is an area of significant public interest.

The European Union (EU) Council Directive 2010/45/EU of the European Parliament and of the Council of 7 July 2010 on standards of quality and safety of human organs intended for transplantation and Statutory Instrument (SI) No. 325 of 2012 require the Health Service Executive (HSE) to provide publicly available information on procurement and transplant activities annually. Furthermore, the Human Tissue (Transplantation, Post-Mortem, Anatomical Examination, and Public Display) Bill 2018 will provide for an organ donation register in Ireland. This has implications for the HSE ODP in the processes leading to organ donation. There are numerous international recommendations for the development of audit for deceased donations (Committee of Ministers, 2006; ODEQUS, 2014). Examples of audit in other jurisdictions have demonstrated improvements in care processes and organ donation rates.

ODTI commissioned the National Office of Clinical Audit (NOCA) to undertake a feasibility study to appraise the need for a national clinical audit of organ donation practices. The objective was to complete a review of national and international datasets on organ donation and, to identify processes of care prone to variation that are responsive to measurement and improvement.

ORGAN DONATION SAVES LIVES AND IMPROVES THE QUALITY OF LIFE FOR PEOPLE WITH END-STAGE ORGAN FAILURE. IT INVOLVES THE SELFLESSNESS AND COMPASSION OF ORGAN DONORS AND THEIR FAMILIES SUPPORTED BY DEDICATED FRONTLINE ORGAN DONATION PERSONNEL (ODP) AND ORGAN DONATION TRANSPLANT IRELAND (ODTI).

KEY FINDINGS



A review of international audits in leading countries in organ donation rates identified clinical audit as an important strategy for improvement in organ donation rates. The important features of a Potential Donor Audit (PDA) are:

- a national standard as a prerequisite for clinical audit
- an audit of all deaths in the Intensive Care Unit (ICU) and the Emergency Department (ED)
- data collection by specially trained ODP closest to the organ donation process
- granular-level process data on missed opportunities for organ donation
- provision of information in close to real-time.



A review of national data collections identified a number of existing data within national clinical audits. These audits provide robust and valuable information in their subject areas. Both the NOCA Irish National Intensive Care Unit Audit (INICUA) and the NOCA Irish Paediatric Critical Care Audit (IPCCA) provide high-level organ donation data in the ICU, while the NOCA Major Trauma Audit (MTA) and Out of Hospital Cardiac Arrest Register (OHCAR) may signal untapped potential outside of ICU. The datasets of existing national audits fail to identify all missed opportunities for organ donation and fail to empower the relevant ODP with the necessary information to drive improvement.

RECOMMENDATIONS

1.

Develop a national PDA within one year:

- Implement a PDA in Ireland: Implement the PDA in one hospital in six hospital groups prior to expanding the implementation to all acute hospitals, including paediatric hospitals as organ donation nurse manager (ODNM) resources increase.
- In parallel, develop national guidelines on the organ donation process.

2.

Use existing national audits to highlight potential organ donors across the hospital system, as an interim measure:

- In parallel with the roll-out of a National PDA, and until the PDA is operational in all acute hospitals, use reporting from existing national audits to highlight potential organ donation opportunities across the hospital system.
- The INICUA includes information on potential donor activity.
- Exploring the rates and distribution of deaths from INICUA, IPCCA, MTA, OHCAR, and other national data collections may inform resource allocation over time.

GLOSSARY OF TERMS AND DEFINITIONS

ACRONYM	FULL TERM
ACCORD	Achieving Comprehensive Coordination in Organ Donation throughout the European Union
Assent (to organ donation)	The expression of agreement to organ donation given by a family member
CHI	Children's Health Ireland
CIS	Clinical information system
CLOD	Clinical Lead in Organ Donation
DBD	Donation after brain death
DCD	Donation after circulatory death
ED	Emergency Department
EU	European Union
HSE	Health Service Executive
ICCA	IntelliSpace Critical Care and Anaesthesia
ICD	International Classification of Diseases
ICNARC	Intensive Care National Audit and Research Centre
ICU	Intensive Care Unit
INICUA	Irish National Intensive Care Unit Audit
ICSI	Intensive Care Society of Ireland
INAS	Irish National Audit of Stroke
IPCCA	Irish Paediatric Critical Care Audit
MTA	Major Trauma Audit
NHSBT	National Health Service Blood and Transplant
NOCA	National Office of Clinical Audit
NOPS	National Organ Procurement Service
ODEQUS	Organ Donation European Quality System
ODNM	Organ donation nurse manager
ODP	Organ donation personnel
ODTI	Organ Donation Transplant Ireland
ODP	Organ donation personnel
ODTI	Organ Donation Transplant Ireland
OHCAR	Out of Hospital Cardiac Arrest Register
PDA	Potential Donor Audit

ACRONYM	FULL TERM
PICANet	Paediatric Intensive Care Audit Network
PICU	Paediatric ICU
PMP	Per million population
ROSC	Return of spontaneous circulation
UK	United Kingdom
uDCD	Uncontrolled DCD refers to organ retrieval after a cardiac arrest that is unexpected and from which the patient cannot or should not be resuscitated (NHSBT, 2021)
WLST	Withdrawal of life-sustaining therapy

CAPTURING PATIENT PERSPECTIVES

“A light in the darkness is how I think of organ donation.”

Martina Goggin, Patient and Public Interest Representative, Potential Donor Audit Feasibility Study Steering Committee

When our son Éamonn suffered severe head injuries in a road crash in our home village of Spiddal, County Galway in 2006, our world changed utterly. From sitting chatting in our kitchen on a Friday evening, some hours later we stood by his bedside and looked on in disbelief as our tall, strong son was now breathing through tubes and machines. He was five days on life support in intensive care. And as the days went by and the nights turned to dawn we waited as tests were carried out, and prayed for the miracle that sometimes happens; but all the while dreading that phrase which we hardly understood, that our son was brain-stem dead.



The day before the devastating news was broken to us, we were spoken to gently and sensitively about the possibility of donating Éamonn's organs should he not pull through. It was not an agonising decision for us to make, as Éamonn and I had, by chance, a very brief conversation some months earlier. So thankfully we knew what his wishes would be. What an important conversation that was and how important it was to us that we were subsequently approached about organ donation. This was the moment when, even though we dreaded the possible impending harrowing news, a tiny light began to shine in the darkness around us – the possibility that Éamonn's death might not be entirely in vain.

I will be forever grateful to the medical staff for their kindness, sensitivity and understanding of our utter helplessness during those five days in intensive care, and particularly for giving us the opportunity to be part of Éamonn's last day as he was prepared by the specialist team for donation.

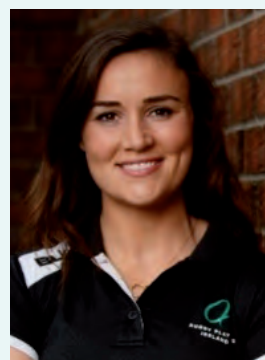
Our overall experience informs the views expressed in my contribution to this feasibility study, and I appreciate the opportunity of having them included. They may, in some way, help ensure that sensitive and timely communication with the family of a potential donor is of paramount importance. They may also ensure that the family should never feel left out of the decision-making or feel they are superfluous in the organ donation/transplantation proceedings.

The benefits of organ donation to the family of a donor cannot be overemphasised, as the comfort and consolation in knowing your loved one has made the noblest act of generosity by giving the gift of life to others is like a light that continues to shine even on the darkest days/

Louise Galvin, Public and Patient Interest Representative, Potential Donor Audit Feasibility Study Steering Committee

Through my personal and professional life I have experienced first-hand the organ donor process in Ireland. As a chartered physiotherapist, I have worked first-hand with patients awaiting and having received transplants. More pertinently, however, I have lived the devastating experiences of the donor family.

Throughout this process, I have felt a real desire for the donor family perspective to be taken into consideration. I felt it provided an opportunity to impact change in a positive way, through sharing that lived experience. Organ donation is a profoundly difficult process for all involved and it must be acknowledged that time is a precious commodity throughout this process. Practically, information must be delivered unambiguously, empathetically and by experienced healthcare professionals who are available to answer questions from the donor family. Having this process streamlined and standardised nationwide will lead to a more holistic experience for the donor family, and ultimately maximise procurement of organs.



Finally, nothing prepares you, or consoles you, for the sudden loss of a loved one. However, there is some solace in knowing their passing has afforded others with the gift of life.



CHAPTER 1 **INTRODUCTION**

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CHAPTER 1: INTRODUCTION

1.1 ORGAN DONATION

It is widely acknowledged that organ donation and transplantation save lives and improves the quality of life of patients with organ failure. In 2019, some 85 families in Ireland generously donated their loved ones' organs (ODTI 2019). There are currently 627 patients awaiting transplants in Ireland (Organ Donation Transplant Ireland (ODTI), 9 September 2021, personal communication). However, there are more people in need of an organ transplant than there are organs available for transplantation.

Organ donation is a relatively infrequent occurrence. It tends to happen outside of routine working hours. Healthcare workers therefore need to be supported in their work practices in making the consideration of organ donation a routine part of end-of-life care in appropriate patients (Murphy and Smith 2012).

1.2 CLINICAL AUDIT IN ORGAN DONATION

There have been numerous international recommendations for the development of quality assurance programmes for deceased donations (Committee of Ministers. 2006; European Commission 2009).

A structured quality improvement/assurance programme incorporating audits and evaluation of programme performance, using methods such as death record reviews, analysis of quality indicators, efficiency indices, and benchmarking methods, is associated with higher levels of performance and is a key factor in overcoming the challenge of increasing organ availability worldwide (Silva e Silva *et al.* 2021). Quality improvement has been identified as one of 16 factors associated with effectiveness in organ donation (Silva e Silva *et al.* 2021). Internationally, continuous clinical audit provides essential information on the potential for organ donation, highlighting areas for improvement (de la Rosa *et al.* 2012; NHSBT 2020).

In the Irish context, the first national audit on organ donation in Ireland was a retrospective survey of all deaths in Intensive Care Units (ICUs) (Hegarty *et al.* 2010). Dr Helena Ferris was commissioned by the ODTI and the National Quality Improvement team to conduct an audit using Report 15 from the Irish National ICU databases, which was published in a special focus chapter in the Irish National ICU Audit (INICUA) national report 2018 (Ferris *et al.* 2018; National Office of Clinical Audit 2020).

Currently, in 2021, ongoing national (but limited) organ donation activity is captured through the INICUA (Chapter 4) and the Irish Paediatric Critical Care Audit (IPCCA) (Chapter 5). Local level data are available through local INICUA databases (Chapter 4) and specific initiatives by ICU personnel, for example at Children's Health Ireland (CHI) Crumlin and CHI Temple Street, and organ donation personnel (ODP) (Chapter 5).

1.3 THE FEASIBILITY STUDY

ODTI commissioned the National Office of Clinical Audit (NOCA) to undertake a feasibility study to build on previous work and appraise the need for a national clinical audit of organ donation practices. The objective was to complete a review of national and international datasets on organ donation to identify processes of care prone to variation that are responsive to measurement and improvement. This involved considering a variety of possible national clinical audit designs with due regard to:

- international experience
- current guidelines
- the empirical literature
- relevant legislation
- the level of granularity required to drive improvement
- Existing and necessary resources.

The scope of the feasibility study extended to all people who die in acute Irish hospitals. This includes both adults and paediatric patients who die in either the Emergency Department (ED) or in ICU. The scope relates to solid organs only.

This study was clinically led by Dr Alan Gaffney, Clinical Lead in Organ Donation at RCSI Hospital Group and Consultant Anaesthetist and Intensivist at Beaumont Hospital, Dublin. A steering committee (Appendix 1) was established to oversee this work.

The study used the following approach:

- a review of international Potential Donor Audits (PDAs) in leading countries in organ donation
- detailed gap analysis between the INICUA and a leading international PDA dataset (National Health Service Blood and Transplant (NHSBT), personnel communication, 17 August 2021)
- a review of national and local data in Ireland
- a survey of all ODP and ODTI to explore the value of existing national data and the additional data elements necessary to drive improvement.

1.4 KEY DRIVERS OF THIS WORK

Ensuring good-quality ongoing information to support the organ donation process is important. The need for a national clinical audit to identify missed opportunities for organ donation activity was identified by ODP and ODTI.

- There is consistent evidence that at every stage of the clinical pathway opportunities for donation after brain death (DBD) and donation after circulatory death (DCD) are lost in all European member states (European Commission 2009). There is an opportunity to improve the rate of organ donation in Ireland, however. Out of 72 countries worldwide, Ireland ranks 28th in terms of organ donation rates (Global Observatory on Donation and Transplantation 2021). World leaders in organ donation have rates in excess of 45 per million population (pmp) compared with Ireland at 18 pmp (Global Observatory on Donation and Transplantation 2021).
- The organ donation community requires relevant information to drive improvement. This study examines international PDA datasets and national audits and surveys stakeholders to identify the relevant data needed for improvement in Ireland.
- Legislative drivers include compliance with European Union (EU) Council Directive 2010/45/EU and Statutory Instrument (SI) No. 325 of 2012 on data collection for publication annually in relation to organ donation and the Human Tissue (Transplantation, Post-Mortem, Anatomical Examination, and Public Display) Bill 2018, which includes a soft opt-out consent (EU Council Directive 2010/45/EU ; Statutory Instrument (S.I) No. 325 of 2012. ; Department of Health 2020).
- Press and media play a role in encouraging organ donation (Madden *et al.* 2020). In 2015, Ipsos MRBI carried out a survey of over 1,000 people to identify the level of support for organ donation in Ireland. More than 80% of respondents said they would be willing to donate their own organs, while 85% said they would be willing to donate the organs of a close family member (Ipsos MRBI 2015).

1.5 WHO IS THIS REPORT AIMED AT?

This report is intended for a range of audiences, including commissioners, healthcare policymakers and providers, patients, and the public at large. For commissioners and healthcare policymakers, it makes recommendations for a new National PDA. For healthcare providers, it makes a secondary recommendation to use reporting from existing national audits to highlight potential organ donors across the hospital system as an interim measure to inform resource allocation.

This report is presented in two parts:

- The full report presents the methods, findings, and recommendations of the feasibility study.
- The executive summary report presents key messages from this report.



CHAPTER 2

THE PATIENT AND FAMILY JOURNEY TO ORGAN DONATION

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CHAPTER 2: THE PATIENT AND FAMILY JOURNEY TO ORGAN DONATION

2.1 INTRODUCTION

This chapter describes the organ donation pathway taken by potential organ donors and their families from injury or illness through to death. By understanding this pathway and the points where clinical decisions are made, treating clinicians and ODP can identify:

- processes of care prone to variation
- areas for improvement
- potential data acquisition points for clinical audit.

2.2 METHODOLOGY

Members of the steering committee were consulted to describe the organ donation pathway.

2.3 FINDINGS

The organ donation process comprises a number of decisions and processes of care. This is described and illustrated in Figure 2.1.

Only a small proportion of patients (<1%) die in circumstances where organ donation may be possible. Most patients who die and become organ donors have suffered a devastating brain injury due to injury, stroke, including cerebral haemorrhage, or lack of oxygen to the brain (NHSBT 2019b). In the vast majority of circumstances, patients who become organ donors die in ICU having first presented to ED or from the ward.

In Ireland, death is diagnosed when either/or:

- The brain has died despite the heart, lungs, and other organs being artificially supported by drugs and machines (death by neurological criteria or brain death).
- The heart has stopped (death by circulatory criteria or cardiac death).

Patient admitted to ICU from Emergency Department or ward

Patients who suffer a devastating brain injury may die before getting to hospital, may be brought to ED, or may already be a patient on a ward in the hospital.

Many patients die in ED or on the ward before ICU admission is possible. Some die because they are unresponsive to therapy, despite full medical and/or surgical management. In these cases, organ donation is generally not possible. Other patients die because a decision is made to withdraw life-sustaining therapy when the injury is so severe that continuing active management will not lead to an acceptable outcome for that patient. It is important that organ donation is considered in all cases where end-of-life decisions are being made, as this may be an important option for families.

On occasion, where it is likely that a patient on artificial ventilation (breathing) in ED has died (brain death), that patient may be transferred to ICU solely for the purpose of performing clinical brainstem testing and facilitating organ donation where that was the wish of the person and their family.

In other jurisdictions, such as Spain, where resuscitation after cardiac arrest in ED is unsuccessful (cardiac death), certain patients can with family assent go on to become organ donors by artificially supporting their organs using machines and drugs. This is illustrated in Figure 2.1. This

type of routine organ donation model (i.e. uncontrolled donation after circulatory death (uDCD)) has not been developed in the Irish context to date.

Other than the relatively uncommon cases of ICU admission to facilitate organ donation, the primary aim of ICU admission is to save lives. Patients who have a potentially treatable condition are transferred to ICU. Because they are unconscious, they require artificial ventilation through a breathing tube inserted into their airway.

Donation after brain death

Despite full and active management, some patients in ICU fail to respond to therapy and become brain dead. Organ donation can often be offered as an option to family members because the patient's organs can be protected from severe damage using drugs and machines, despite the death of the brain.

In order to diagnose brain death, the following steps must occur:

- recognition that the criteria for brainstem testing have been met
- confirmation that the criteria for brainstem testing have been met
- performance of clinical brainstem testing
- confirmation of brain death based on clinical brainstem testing.

The diagnosis of death through brainstem testing has implications for the patient and the family beyond whether the patient or the family would like organ donation to occur and should take place independently of organ donation considerations.

The Intensive Care Society of Ireland (ICSI) published guidelines on the diagnosis of brain death in 2020 (Intensive Care Society of Ireland. 2020). In Italy, it is legislatively mandated that brainstem testing should occur when the criteria for testing have been met (Chapter 3).

The process of organ donation following brain death usually allows for the maximum number of organs to be donated, as the organs can be maintained in an optimum condition after death and prior to donation.

Donation after circulatory (cardiac) death

Despite full and active management, some patients fail to respond to therapy. Some patients will die by cardiac death. In only a small number of cases is it possible to offer the option of organ donation to families as the patient's organs may have become severely damaged during the dying process. Other patients will die following withdrawal of life-sustaining therapy (WLST). In a small number of these cases, organ donation can be offered as a possibility to family members if it is likely that the person will die relatively soon after WLST, thereby limiting organ damage. In order to offer the possibility of organ donation to a family in the circumstance of circulatory death following the WLST, it is important that organ donation is considered in all cases where end-of-life decisions are being made.

The Intensive Care Society of Ireland published guidelines on DCD in 2016 (Intensive Care Society of Ireland. 2016).

Referral to organ donation personnel

Referral of the patient to ODP is appropriate for every potential donor. This is the case whether in ED on the ward or in ICU.

ODP can advise if the patient may be a suitable candidate for organ donation, assist in family approach, and support the healthcare professionals and families throughout the donation process.

Organ donation personnel

In Ireland, ODP currently consist of:

- Six Hospital Group clinical leads in organ donation (CLODs)
- Six Hospital Group organ donation nurse managers (ODNMs)
- The National Organ Procurement Service – eight clinical nurse managers and one assistant director of nursing.

All families should be approached about the possibility of organ donation after they have had time to process information communicated to them regarding a devastating prognosis and after they have understood the diagnosis of death or imminent death.

Communication needs to be delivered sensitively and professionally by the right person at the right time and the message needs to be clear and honest (Marck *et al.* 2016; Organ and Tissue Authority 2019). Specialist ODP ensure good practices are in place and that relevant staff have the skills and training when meeting with a potential donor family (ODTI 2015).

National Organ Procurement Service

Once the patient's family has assented to organ donation, they are met by the National Organ Procurement Service (NOPS), who obtain the necessary written agreement to proceed to organ donation and who complete the Health and Lifestyle Questionnaire.

NOPS coordinates the organ retrieval process from referral to completion of organ retrieval in the operating theatre, at which point the organ donation process is complete.

Paediatric donation

Children may also be considered as potential organ donors. While the journey of the patient and family is similar in both adult and paediatric patients, the medical and surgical conditions leading to the death of the paediatric patient are often due to different conditions than those commonly encountered in adult medicine. Neonatal donation in Ireland does not include solid organs but does include heart valve tissue.

2.4 SUMMARY OF FINDINGS

Organ donation is a rare event. In order to ensure that organ donation is offered as an option in every circumstance where organ donation is possible, it is necessary to:

- recognise that a patient may be an organ donor should they die
- provide the medical and family support to facilitate donation should that be the patient's or family's wish
- perform brainstem testing where the criteria for testing are met
- consider organ donation where a decision is made to withdraw life-sustaining therapy
- refer all potential organ donors to ODP
- approach the family in the right way at the right time by the right person
- support the family and staff throughout the organ donation process.

2.5 IMPLICATIONS FOR THE FEASIBILITY STUDY

Describing the process highlights the complexity of organ donation. It shows the points at which there is potential for variation in the processes of care influencing whether or not organ donation occurs. It describes where potential data acquisition points can potentially be audited. Specific national guidance on the complete process, especially on the detection of the potential donor, referral to ODP, family approach, and paediatric donation, would be welcome to help ensure that organ donation is considered in every situation where it is possible and to act as a best practice standard against which practice can be measured.

CHAPTER 3

INTERNATIONAL DATA COLLECTIONS

The background of the page is a dark blue gradient. In the lower half, there is a stylized representation of a globe. The globe is composed of a dense grid of small, light blue dots. Overlaid on this globe is a network of white lines connecting various points, some of which are larger and brighter than others, creating a sense of global connectivity and data flow.

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CHAPTER 3: INTERNATIONAL DATA COLLECTIONS

3.1 INTRODUCTION

In order to inform the development of a suitable national clinical audit pathway for the potential donor in Ireland, it is appropriate to seek expertise from other jurisdictions that have significant experience in audit development. The aim of this chapter is to describe the international experience of audit. It summarises the main characteristics of five existing national programmes and one regional programme across European countries and Australia. It also describes clinical guideline availability and variability in processes of care to provide Irish stakeholders with references against which to compare processes of care in this jurisdiction.

3.2 METHODOLOGY

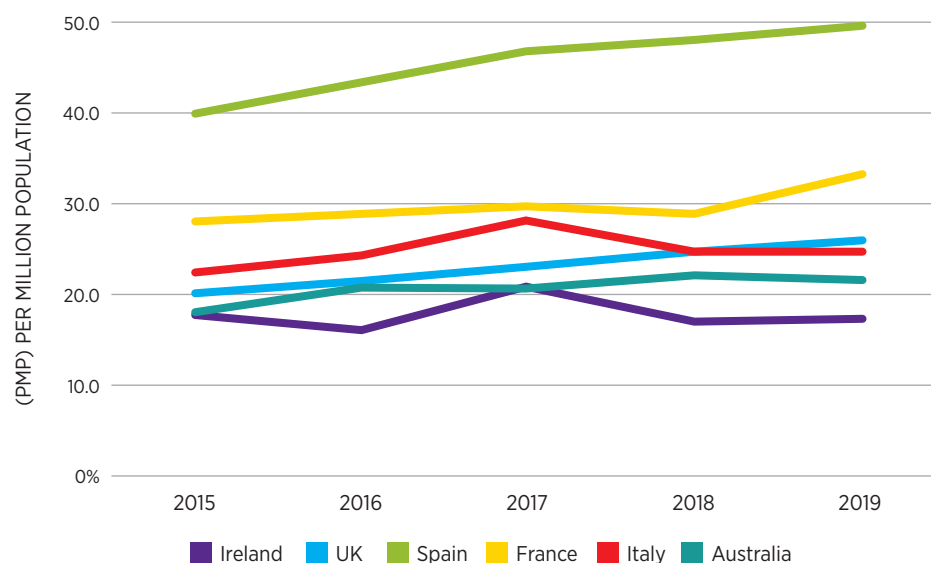
A comprehensive consultation process was undertaken by the Clinical Lead and NOCA researcher with national and international experts in organ donation, data collection, and audit (see Appendix 2 for a full list of consultations). Supplementary information was also reviewed where available, including national reports and publications, guideline documents, the empirical literature, and visual demonstrations of the audit data input and reporting tools.

Countries were included if they had:

- established national or regional quality assurance programmes for deceased donation, including a number of hospitals
- pmp greater than Ireland and demonstrated improvement over time
- widely known experts, with a record of leadership in the field of PDA with a willingness to engage in the feasibility study.

3.3 FINDINGS

Out of 72 countries worldwide, Ireland ranks 28th in terms of organ donation rates (Global Observatory on Donation and Transplantation 2021). Rates of organ donation are 18 pmp compared with 25 pmp in the United Kingdom (UK) and in excess of 45 pmp in Spain. Australia, France, Italy, Spain, and the UK are widely known across organ donation clinical, research and improvement communities for their approaches to clinical audit and quality improvement. Their rates of organ donation pmp are greater than Ireland and have improved over time (see Figure 3.1). Measurement of donation rates and performance most commonly use the blunt metric of actual donors per million (living) population. However, from the perspective of improvement, this is limited, as it does not account for the potential donor pool which is dependent on rates and causes of death, i.e. it does not consider the total theoretical maximum organ donor rate (Pilcher *et al.* 2015). Nevertheless, this is the primary measure used to examine performance in organ donation. Each of the international data collections are characterised and described in detail below.



Source: (Global Observatory on Donation and Transplantation 2021)

FIGURE 3.1: RATES OF ORGAN DONATION OVER TIME (PMP)

Characteristics of international data collections

A summary of the characteristics of international data collections is presented in Table 3.1. Cumulatively, these findings represent at least 47 years of expertise, learning, and development, specifically in the area of national clinical audit of the potential organ donor. The international audits were characterised based on the Health Service Executive's (HSE) *Practical Guide to Clinical Audit* in terms of design elements (who/how/where), standard selection, and measuring performance (HSE 2013). The categories described are as follows:

Data collector: For a clinical audit to be successful and achieve its aim and purpose, it needs to involve the right people with the right skills from the outset. Therefore, the identification of skills required and of individuals possessing these skills are included.

Data collection method: This relates to the process of data collection being prospective (during the course of the process before the outcome of interest) or retrospective (from medical records after the outcome of interest). This was a unique discussion item in all of the consultations with international experts.

Setting: This relates to the areas of the hospital included in the audit.

Population: This relates to the patient selection criteria included in the audit.

Standard/criteria selection: A standard describes and defines the quality of care to be achieved and is a prerequisite for national clinical audit (Health Service Executive. 2019).

Measurement: This relates to patient demographics, measurement of processes and outcome of care.

Method of reporting: This relates to how information is disseminated from the audits.

TABLE 3.1: THE CHARACTERISTICS OF INTERNATIONAL POTENTIAL DONOR AUDITS

Country (tool/audit name) Year commenced	Data collector	Data collection method	Setting	Population	Standard	Descriptive and performance measurement	Outcome mea- surement	Method of reporting
Australia (DonateLife Audit) 2012	Donation nurse specialist	Retrospective	ED, ICU and those who died from an irrecoverable brain injury recently discharged (<24 hours) from ED or ICU	All intubated patients who died aged between 28 days and <80 years or any other patient outside the above criteria referred to DonateLife Agency/ specialist who thought donation potentially feasible for that patient	<i>Best Practice Guideline for Offering Organ and Tissue Donation in Australia</i> (Organ and Tissue Authority 2021)	Baseline patient characteristics / eligibility criteria; referral dates and outcomes; end-of-life care; donation discussions and outcomes, including reasons, medical suitability, health conditions, laboratory and imaging results related to cardiac, renal, pancreatic, hepatic, and respiratory functions. Referral rates; family donation conversation; consent rate; reasons why family declined; donation rates (DBD, DCD)	Referral rates (key performance indicator 100%); request rates; predicted consent rate; actual consent rate; conversion rates	Dashboard available nationally and for each state and hospital. Reports to chief executives and Ministry of Health
Australia (New South Wales Organ and Tissue Donation Service referral log)	Donation nurse specialist	Prospective: medical record audit of every patient referred to ODP	ICU	Every patient on an end- of-life care pathway	<i>Best Practice Guideline for Offering Organ and Tissue Donation in Australia</i> (Organ and Tissue Authority 2021)	Best practice elements of the family donation conversation; clinical timelines; and reasons why potential donors do not actualise	Review of all the decisions not suitable to proceed within a month in order to ensure consistency of decision- making and compliance with best-practice/ donor suitability guidelines. Audit of compliance with national <i>Best Practice Guideline for Offering Organ and Tissue Donation in Australia</i>	Monthly local/regional reporting

Country (tool/audit name) Year commenced	Data collector	Data collection method	Setting	Population	Standard	Descriptive and performance measurement	Outcome measurement	Method of reporting
France (Formulaire D'enquête Décès – Death Survey Form) 2001	ODP (hospital coordinator)	Prospective	ICUs and selected units of interest (e.g. ED, Neuro)	All patients who died	Organ Donation European Quality System (ODEQUS 2014)	General information: cause and time of death; Characteris- tics of the patient: were there severe neurological signs and a Glasgow Coma Scale of <3, were the criteria for death by neurological criteria met?; absolute contraindications, consent/authorisa- tion including family approach, was the interview prepared, was the interview subject to analysis?; therapeutic limita- tions (DCD pathway); outcome including reasons why actual donation did not proceed	Deaths; possible donors (Glasgow Coma Scale <3 minus con- traindications); actual donors	No national reporting; hospital level only
Italy (National Registry of Deaths with acute cerebral lesion in ICU) 2006	Local ICU transplant coordinator	Prospective	ICU	All deaths in ICU from a devastating brain injury (predefined list of ICD-10 codes from ACCORD)	Ministry of Health Decree; national indicators	Hospital procurement coordinators monitor, document, and evaluate all the ICU deaths with acute cerebral lesions; brain death declaration; family opposition; actual and utilised donors	In line with national healthcare indicators	National Transplant Centre monthly report Hospital, regional and national data available
Italy (National Organ Donation Programme) 2018 and 2020	Local ICU transplant coordinator	Retrospec- tive	ICU	All deaths in ICU from a devastating brain injury (predefined list of ICD-10 codes from ACCORD)	Ministry of Health Decree; national indicators	Compliance with referral; planning at end-of-life care; donation specialists involved; national register checked	National quality indicators; relation between brain deaths declaration and total number of deaths with acute cerebral injuries; number of brainstem deaths; number of actual donors (pmp)	Annual reporting (legislatively mandated) as part of the 'essential healthcare levels' indicators

Country (tool/audit name) Year commenced	Data collector	Data collection method	Setting	Population	Standard	Descriptive and performance measurement	Outcome measurement	Method of reporting
Spain (Quality Assurance Program in the Donation Process) 1998	Transplant coordinator	Retrospective	ICUs (data in other relevant units can also be collected)	Patient with a clinical condition consistent with brain death	<i>Good Practice Guidelines in the Process of Organ Donation</i> (National Transplant Organisation 2011)	Demographic and clinical information; consent; judicial authorisation; referral to transplant coordinator and reasons why not; causes why identified potential donors were not converted into actual donors are assessed: brain death diagnosis not completed, medical unsuitability, main- tenance problems, refusal of permission for organ donation, judicial refusal, lack of appropriate recipi- ents or organisational problems	ICU deaths; potential donors; ¹ actual donors; potential of donation; conversion rate; causes of losses	Quarterly to the critical care unit; annually to the hospital
	Transplant coordinator	Retrospective	ICUs	Non-referred potential donors	<i>Good Practice Guidelines in the Process of Organ Donation</i> (National Transplant Organisation 2011)	Assessment of criteria applied for the identification of potential donor cases in the retrospective review of clinical charts: confirmed, highly probable, possible potential donor	ICU deaths; potential donors; ¹ actual donors; possible donors ²	Annual

¹ Confirmed and highly probable cases of potential donors (i.e. meeting the criteria for brainstem testing/brain death confirmed) plus some additional criteria (de la Rosa *et al.*, 2012).

² The number of possible donors is calculated by subtracting the unavoidable losses from the identified cases of potential donors.

Country (tool/audit name) Year commenced	Data collector	Data collection method	Setting	Population	Standard	Descriptive and performance measurement	Outcome measurement	Method of reporting
UK (National Health Service Blood and Transplant (NHSBT)) 2003	Specialist nurse in organ donation	Prospective	ICU and ED	All deaths aged 80 and under	NHSBT <i>Best Practice Guidance</i> ; National Institute for Health and Care Excellence (NICE) Guidelines	Patient information; referral; organ donation services attendance; ventilation; absolute contraindications; organ-specific contraindications; donors after neurological death; sedatives; preconditions for neurological testing; neurological testing; donors after circulatory death; exclusions; patient donation decisions; donation decision conversations; outcome	Donation rate pmp; consent rate	Real-time reporting available to the specialist nurses in organ donation; national and regional findings reported annually; local data available upon request
UK (Intensive Care National Audit and Research Centre (ICNARC)) (soon to be discontinued) 1996	ICU audit nurse	Retrospective	ICU	All patients	NA	NA	Unit non- survivors; organ donation by unit; DBD and DCD donors as a percentage of all deaths	National and local finding reported quarterly and annually

DESCRIPTION OF INTERNATIONAL DATA COLLECTIONS

Australia

The DonateLife Audit is a systematic national approach to reporting on all actual and potential organ donation activity, donor identification, request and consent rates, reasons why donation does not proceed, and missed donation opportunities. Data are retrospectively collected on all deaths for patients who died aged between 28 days and 80 years in ED, ICU, or on the wards if discharged from the ED or ICU in the previous 24 hours, and deaths of any other patients where organ donation is considered.

DonateLife uses a web-based data collection tool. The elements collected have been refined over time and now include detailed physiological and laboratory data, in addition to patient demographics, brain death status, end-of-life process, and communication with the family about donation (who/where/when). Using this style of robust data collection tool, it is possible to estimate the expected number of organ donors. This may assist benchmarking of donation outcomes. It is also possible to estimate a predicted consent rate based on modifiable and non-modifiable factors which can be compared to actual consent rates. These comparative data can be powerful in influencing change. DonateLife do not publicly publish their audit findings.

The audit has recently been enhanced to provide regular, interactive dashboards to the relevant hospitals and jurisdictions (DonateLife, 26 May 2021, personal communication). There is no penalty for low performance. Rather, data are used positively to influence quality improvement.

New South Wales OTDS Referral Log

The New South Wales (NSW) Organ and Tissue Donation Service (OTDS) referral log prospectively collects data from all DonateLife network hospitals (n=20) in NSW, i.e. it includes all hospitals that have a donation specialist nurse and other district/rural hospitals linked to a network hospital donation specialist nurse. This is a separate data collection tool to the DonateLife audit.

Patients meet the inclusion criteria for referral where they are ventilated and there is planned end-of-life care, with no upper age limit, in ICU or ED. There are no age or cancer exclusions. The referral log only captures referrals and has no role in identifying non-referrals.

This audit includes a detailed assessment of compliance with the national *Best Practice Guideline for Offering Organ and Tissue Donation in Australia* (2nd edn) (Organ and Tissue Authority 2021). There are five essential elements in the guideline for running family donation conversations: routine referral to DonateLife; communicating end-of-life; planning the approach; discussing donation; and reviewing practice. The database has some additional fields, for example, for actual donors there is a retrieval section that collects information on retrieval timelines.

There are a large number of pre-formatted reports that all users can generate from the database, in addition to a simple time-based export to an Excel file. The database is an online SharePoint database that is maintained in-house. A breakdown of compliance with the best practice elements for donation conversations is sent to the local donation teams quarterly (although they can track this themselves at any time). All cases that do not proceed to organ donation are reviewed within a month with the transplant centres in order to ensure consistency of decision-making and compliance with best-practice / donor suitability guidelines. There are at least annual meetings in each of the 20 hospitals with the donation team and the district executives, at which annual data are reviewed, and an annual clinical meeting with the donation team and the NSW organ donation service executive to explore issues at a more granular level.

France

The French national quality assurance programme is based on the Organ Donation European Quality System (ODEQUS 2014). ODEQUS is a quality system for the organ donation process with quality criteria for best practices and quality indicators for DBD, DCD, and living donation. These guidelines emphasise the systematic approach to the identification of the possible organ donor in every end-of-life care pathway. Each hospital has a committee that assesses the degree to which each of the 35 national standard categories are met. The self-assessment framework consists of 35 recommendations divided into 14 chapters that govern the end-to-end organ donation process and the infrastructure and resources required. Each recommendation is defined by specific criteria.

This framework has sections specific to the potential donor. It includes areas such as that a method to inform of the existence of potential organ donors in real-time exists; that a procedure for identification is defined; that the procedure for identifying potential organ donors is updated, validated and familiar to healthcare professionals; that the hospital coordinator is called as soon as clinical signs of potential brain death appear; and that reasons for not proceeding with organ donation are analysed and followed up. Recommendations for the management of the potential donor include areas such as the declaration of death; communicating the death to family members in the presence of the hospital coordinator; and planning the family approach. Furthermore, examination of the reasons for families not assenting to organ donation is conducted in conjunction with the hospital coordinator in accordance with hospital policy. Results of self-assessment are presented to the relevant healthcare professionals and partners in the sector who collaborate to set quality improvement plans.

The audit tool described in Table 3.1 is used to measure the degree to which national standards are met. There is no national collation of data, even though most hospitals use the same approach and same software. As a result, there is currently no benchmarking.

Italy

Since 2006, data for all deaths with acute cerebral lesions in Italian ICUs are collected by hospital coordinators and inputted into a national registry maintained by the Italian Transplant Information System (established by law on 1 April 1999, number 91). This approach estimates the maximum organ donation potential of individual wards, hospitals, and regions. Data analysis is carried out on de-identified data. The registry includes patients who die in ICU with a primary or secondary acute cerebral lesion irrespective of aetiology and age. Multiple-trauma patients who die without signs of a cerebral lesion are excluded.

There are a number of national indicators:

- **Indicator 1 (Proc O):** the rate of ICU deaths with an acute cerebral lesion (per million population). This is an indicator of the effectiveness of the system and highlights how many deaths occurred in ICU in subjects with severe brain injuries (patients with the potential to develop brain death in ICU), a minimum requirement for organ donation. The national value in 2020 is 79.1. There is, however, wide regional variation, between a minimum of 17.8 in Basilicata and a maximum of 154.7 in Friuli Venezia Giulia. The National Transplant Network Report 2020 states that “the regional epidemiology of deaths does not explain such variability, it could be linked to the appropriateness of intensive care admissions (with the exclusion of patients who die in wards other than intensive care), but also to the inadequate reporting in the national registry of all patients who die in intensive care with cerebral lesions”(Centro Nazionale Trapianti {National Transplant Centre} 2020). Thus, data of the national registry are compared offline with the ICU deaths selected by ICD-10 codes of acute cerebral damage (ACCORD European Project) to measure the coordinator efficiency in possible donor detection. Recently, all the hospital deaths with acute cerebral lesion ICD-10 codes (ICU, ED and wards) are considered.

- **Indicator 2 (Brain death pmp):** the number of brain death declarations per million population. In Italy, brain death declaration is mandatory by law regardless of organ of donation potentiality (medical contraindications, opposition, etc.). All brain death declarations must be referred to the regional/national coordination centres. There is wide regional variability (from 11 pmp to 104 pmp). Missing brain deaths are the most critical factor in the donation process and should be audited taking into consideration data of clinical records.
- **Indicator 3 (Organ donors pmp):** the rate of actual organ donation per million population. While the national average in 2020 was 21.54, there is wide regional variability from 0 to 57.1.
- **Indicator 4 (Proc 1):** the percentage of deaths with brain damage that become actual donors ('Conversion' rates). Proc 1 values are reported as a proportion of Proc 0 values to describe donation efficiency. The average Italian value for 2020 was 25.5%.
- **Indicator 5 (Proc 2):** the percentage of ICU deaths with a brain lesion that are confirmed deaths by neurological criteria.
Brain deaths should be 50–65% of all the ICU deaths with acute brain lesion. Even if the national average value is 47.8, both inadequate reporting of deaths with brain lesion and missing brain death detection/declaration may affect regional Proc 2 values. These values are checked offline using hospital discharge codes (ICD-9/10) as auditing data.

Since 2017, indicators 2, 3 and 5 have been included in the national system (Ministry of Health Decree, 12 January 2017) and are utilised for evaluating the efficiency of regional healthcare (essential healthcare levels). If opportunities for brain death declaration and organ donation are missed, improvement measures supporting ICU, hospital, and regional organisation educational programmes are identified. If organ donation rates remain low despite local supports, organisation, diagnostic/therapeutically pathways, and personnel changes may even be considered.

Internal audits are performed by hospital coordinators. Committees from regional transplant centres and the national transplant centre carry out external audits every two years (hospital and regions, respectively). Committees may include external experts.

In some patients, even if clinical criteria for brain death are fulfilled, brainstem testing is not always performed, leading to a number of missed potential DBD donors. There are multiple reasons for this, including ICU capacity, personnel and bed shortages, issues with family approach, attitudes toward organ donation, and management of end-of-life processes, etc.

DCD is at an early stage in Italy (around 100 potential donors in 2020 in only five of 21 regions). Potential DCD donors are not currently audited.

Spain

Spain is the European leader in organ donation. The rise in the donation rate in Spain, from 14.3 pmp in 1989 to 49.61 pmp in 2019, has been attributed to multiple strategies, including potential organ donor audits in hospitals and a proactive donor detection programme. Good practice guidelines were developed which focus on practices, protocols, particular skills, and profiles regarded as crucial for success at best-performing hospitals. Since the implementation of these guidelines in January 2011, there has been a notable increase in the number of interannual absolute number of deceased organ donors, from 1,502 at 31 December 2010 to 1,718 at 31 March 2012, which means an increase from 32.1 to 36.4 donors pmp, and with a parallel 11.6% increase in solid organ transplantation (Matesanz *et al.* 2012).

The Spanish Quality Assurance Program in Deceased Donation Process (QAPDD) was developed by the Spanish National Transplant Organization (ONT) in 1998 and focuses on the process of DBD. It was developed with three objectives: (1) to estimate the potential of deceased donation; (2) to evaluate the performance of the organ donation process, including analysis of the reasons for losing potential donors, and its ability to identify areas for improvement; and (3) to describe hospital factors which impact on the aforementioned areas. There are also internal and external components to the quality assurance programme (de la Rosa *et al.* 2012).

The internal evaluation consists of a retrospective analysis of the medical records of deaths occurring in ICUs. Each case is further analysed to verify whether the potential donor was referred to the transplant coordinator and, if not, the reasons why so. Between 1999 and 2010, more than 206,000 medical records of all deaths registered in the ICUs of participating hospitals were reviewed. It was found that approximately 1% of potential donors were not referred to the hospital transplant coordination team. From all identified potential donor cases, 54.6% were converted into actual donors (de la Rosa *et al.*, 2012).

In addition to local PDAs, Spain has been conducting external audits over the past 20 years. The purpose of the external audit is to validate the findings of the local hospital internal audits and to continually identify opportunities for improvement in the organ donation process. A positive, collaborative approach is taken in highlighting areas for improvement. Two to three hospitals per region are chosen for external review by regional transplant coordinators. A changeover in organ donation staff or the results of the internal audit may trigger the site selection for an external audit.

Like Italy, Spain considers the national pool of potential donors as those with a clinical condition consistent with brain death. Although this pool has progressively decreased from 65.2 pmp in 2001 to 49 pmp in 2010, the number of actual donors after brain death has remained over 40 pmp up until 2020 (de la Rosa *et al.* 2012; Global Observatory on Donation and Transplantation 2021). While the focus of the Spanish QAPDD is on ICU, the online data entry portal facilitates collection of data in other units such as ED, neurosurgical and stroke wards and ensures consistent data collection in different hospital settings. Spain is currently reviewing its methodology to facilitate the review of patients suitable for DCD.

United Kingdom

The National Health Service Blood and Transplant (NHSBT) developed a PDA as part of a series of measures to improve organ donation. The practice in the UK is governed by a suite of guidance documents and resources for best practice which provide the standards for the PDA (NHSBT 2019a). The PDA was created to identify areas along the pathway where donation potential was lost. The original PDA did not audit the DCD pathway, as very few centres practised DCD until approximately 2008. The first revision of the PDA started auditing DCD and created many of the drop-down options and other features designed to help understand and improve practices around the country. The second revision of the PDA was implemented in 2021, requiring more detailed information and giving enhanced options to identify reasons why potential organ donors were lost.

NHSBT published data indicating that family refusal rates vary across the world (9.2% to 45.7%). Variability is also seen across the UK (NHSBT 2017). The UK makes its reports available publicly and strongly encourage an open, transparent, collaborative, and positive approach to quality improvement.

There has been continuous improvement in five-year trends for key numbers and rates across the UK (NHSBT 2020). This includes:

- improved testing rates (from 85% to 87%)
- improved referral rates (from 96% to 99% DBD; from 83% to 91% DCD)
- a reduction in missed referrals from 63 to 19 (DBD) and from 1,099 to 570 (DCD)
- an increase in family approaches where a specialist nurse in organ donation was present, increasing from 91% to 96% (DBD) and from 78% to 89% (DCD)
- the consent rate has increased from 69% to 72% (DBD) and from 57% to 65% (DCD).

In both Spain and the UK, completion of the audit tool is part of the process in the normal working day for the specialist nurses. This facilitates structuring the process according to best practice standards and also maximises the validity of the data, as it is collected in as close to real-time as possible. The UK PDA is now a world-leading audit tool to provide the best data to hospitals as the basis for learning and improvement and to compare donation activity internationally.

3.4 SUMMARY OF FINDINGS

National PDAs in leading organ donation jurisdictions identify the potential donor pool using different methods to maximise the potential for organ donation. Spain, the UK, France, Italy, and Australia audit all deaths in ICU as a minimum and start by identifying all patients who have the potential to be brain dead (e.g. by meeting the criteria for brainstem testing/all deaths with acute cerebral lesions). This is consistent with the World Health Organization (WHO) Critical Pathway for Deceased Organ Donation (Dominguez-Gil *et al.* 2011). In addition to ICU, the UK, Australia, and France also audit deaths in ED. Identifying all those who could be potentially brain dead as a denominator and including both ICU and ED maximises the baseline pool of potential donors.

All international PDAs had national standards. There is strong evidence of improvement in donation rates as a result of implementation of standards (Matesanz *et al.* 2012). The common themes identified from other jurisdictions for national clinical audit include:

- donor identification
- end-of-life care (DBD/DCD)
- referral to ODP
- involvement of ODP
- medical suitability
- assent
- checking the national register
- judicial authorisation
- donation decision conversation
- conversion rates to actual donations.

International PDAs identify missed opportunities for organ donation by exploring reasons why best practice standards are not met. This includes exploring clinicians' end-of-life practices and determining the reasons why families do not assent to organ donation during a difficult and emotional time. This approach requires sensitivity and specialist training to determine the answers to these difficult questions. International guidelines require that the family approach and donation conversations are completed by specialist ODP. Of note, PDA data are uniformly collected by specially trained ODP in every country.

International PDAs broadly have two approaches to national clinical audit:

1. A high-level retrospective national audit, which can be helpful for benchmarking and putting a national lens on donation activity and the degree to which standards of care are met, e.g. referral rate, approach, and assent rate.
2. A granular-level prospective audit, which can identify reasons for missed opportunities and target quality improvement locally, e.g. reasons why those who were potentially brainstem dead were not tested and, reasons why families did not assent.

NHSBT is the most comprehensive approach to national clinical audit that systematically assesses the complete patient and family journey to organ donation. It includes ICU and ED and provides comprehensive reasons why donations do not occur. NHSBT is exploring collaborations with other countries and the similarity of the Australian, French, and NHS approaches offers the opportunity for joined-up analyses in the future.

3.5 IMPLICATIONS FOR THE FEASIBILITY STUDY

Other jurisdictions provide clear guidance and learning on how to improve organ donation rates through availability of guidelines, national clinical audit and, the timely feedback.

- The design of a PDA should measure against a national standard. This is a prerequisite for clinical audit design. Successful national clinical audit designs include the availability of national clinical guidelines and standards of care and establishing the appropriate governance and quality improvement strategies. In Ireland, there are the brain death guidelines, DCD guidelines, and the management of the potential organ donor guidelines. However, additional guidelines to complete the organ donation process are required around the identification of the potential donor, referral to ODP, and family donation decisions.
- A prospective audit of all deaths in ICU and ED accurately determines the size of the potential donor pool and identifies missed opportunities for organ donation. Identifying all patients who could be potentially brain dead is important for maximising the potential donor pool.
- Granular information on the processes of care and reasons why best practice standards are not met provides meaningful information to drive improvement to ODP. The international PDAs highlight that this data should be collected by specially trained ODP who are closest to the organ donation process.



CHAPTER 4

NOCA IRISH NATIONAL ICU AUDIT

CHAPTER 4: NOCA IRISH NATIONAL ICU AUDIT

4.1 INTRODUCTION

A dataset on organ donation processes and outcomes is available in the Irish National ICU Audit (INICUA). This feasibility study presents an opportunity to review the INICUA organ donation dataset to assess the degree to which it matches the requirements of a PDA.

This chapter describes the operation of the INICUA and benchmarks the INICUA organ donation dataset against the NHSBT (2021) dataset. PDAs in leading organ donation jurisdictions have a number of similarities. The NHSBT was identified as a 'gold standard' PDA dataset to drive improvement (see Chapter 3).

Description of the INICUA

NOCA established the INICUA in 2013. NOCA works with the Intensive Care National Audit and Research Centre (ICNARC) in the UK, who provides data validation, data analysis, and benchmarking of data between other Irish units and against ICUs in the UK. Currently, there are 26 ICUs in 22 public hospitals taking part in this audit. This covers an estimated 91% of all ICU activity in publicly funded adult hospitals, based on volumes of invasively ventilated patients in 2019. These units report on ICU activity and outcomes using quality indicators that are benchmarked against other participating units across Ireland and the UK.

Until 2021, ICNARC collected a limited dataset on organ donation outcomes in ICU in the UK. This is now being omitted as all organ donation outcomes are collected by the NHSBT PDA.

Reporting

The INICUA governance committee produces national reports and governs the output from INICUA. Local organ donation reports can be provided by INICUA audit coordinators to Hospital Group CLODs and ODNMs after completion of a data access request form in the relevant hospital (see Appendix 4). Participating units in hospitals are expected to review their reports to support quality assurance and improvement.

4.2 METHODOLOGY

Members of the steering committee with expertise in INICUA, organ donation, and audit methodology conducted a benchmarking exercise between the INICUA organ donation and NHSBT datasets.

4.3 FINDINGS

The INICUA and NHSBT collect national data on organ donation for Ireland and the UK, respectively. Important differences exist between the datasets in terms of:

- the denominators
- the level of granularity
- approach to data collection
- availability of reporting

The denominators

- In INICUA, the denominator used in assessing processes of care is 'brain death confirmed'. In NHSBT, it is a patient with 'suspected neurological death' (i.e. meeting the criteria for neurological/brainstem testing). The identification of patients that meet the criteria for neurological death testing broadens the potential donor pool. More of these potential donors could proceed to organ donation if all of these patients were referred to ODP; identification of this potential by audit would support this in the future. This will be included in a revision of the INICUA dataset. However, this information is complex to collect. The NHSBT adds clear information on the circumstances surrounding neurological testing (e.g. stability of the patient) from which the specific opportunities to maximise the potential donor pool can be identified.
- The NHSBT dataset reports on patients with specific eligibility criteria for donation by circulatory death (i.e. a patient whose imminent death was anticipated) rather than reporting on all patients who died by circulatory criteria. This is facilitated by national guidelines on triggers for referral. This is likely a contributing factor for a greater DCD referral rate (1–9% Ireland; 91% UK) and associated outcomes in the UK (2019 data: 1.5 pmp Ireland; 10.3 pmp UK) (National Office of Clinical Audit 2020; NHSBT 2020; Global Observatory on Donation and Transplantation 2021). More information on the circumstances of WLST and of end-of-life in these patients may facilitate a greater referral rate of potentially eligible DCD patients to ODP. This data is also complex to collect.

The level of granularity

Table 4.1 benchmarks the INICUA organ donation dataset against the NHSBT dataset, which clearly demonstrates differences in granularity between the datasets.

- Specific, granular detail in relation to all organ donation processes are available in NHSBT. Granular detail regarding the donation decision conversations (who/where/when/planning) is also available. Detailed lists of reasons why the processes leading to organ donation did not occur (e.g. neurological testing rate, referral, and approach) and why families decline assent for organ donation and non-donation outcome are also available. INICUA audit coordinators can select a limited number of high-level options for reasons for non-donation outcome. The granular information provided in the NHSBT dataset is valuable to understand the sequencing and circumstances around each of the processes involved and to identify specific areas for improvement. Specific reasons for non-consent can identify if these factors are amenable to improvement.
- There is a defined, extensive list of absolute contraindications in addition to organ-specific contraindications in NHSBT, which INICUA capture in one response element 'medical contraindications'. However, it is not clear who makes these decisions and whether they are true or perceived contraindications. Consultants have a role to liaise with ODP around all ICU deaths so this is accurately determined. National guidelines would standardise processes and decision making by ODP.

TABLE 4.1: A COMPARISON OF IRISH NATIONAL INTENSIVE CARE UNIT AUDIT AND NATIONAL HEALTH SERVICE BLOOD AND TRANSPLANT DATASETS

NHSBT PDA dataset	NHS data variables	INICUA organ donation dataset ✓ Captured ✗ Unavailable	Comments
Patient Information	Patient information, admission details, patient demographics and diagnosis, including primary diagnosis, cause of death and date of death, where patient died, gender, ethnicity, religion	✓ Mostly captured (with the exception of cause of death)	Ethnicity will be in the new ICNARC dataset
Referral	Was the patient referred to the Organ Donation Services (ODS) team? If not, why not? Timing of referral to ODS, who was involved, did an ODS team member ever attend? If not, why not?	✓ ODP referral (Y/N) ✗ Specific details around the timing and circumstances of referral	INICUA uses the term ODP to cover ODP including CLODs, ODNMs and NOPS
Ventilation	How was the patient ventilated immediately prior to death? Was this a controlled death? Were attempts made to stabilise the patient?	✓ Ventilation status ✗ Specific details around end-of-life care	
Absolute contraindications	Tickbox response option of 21 absolute contraindications determined by ODP. Separate organ specific list of contraindications available	✓ High-level aggregated information captured	Specific, absolute contraindications and organ-specific contraindications not presented. INICUA (Report 15) aggregates information into 'medical contraindications', with six response options, including organs deemed unsuitable for transplant and outside age criteria. These may be perceived rather than actual contraindications
Donors after neurological death testing	Were the criteria for neurological testing met? Were there continuing effects of sedatives which would prevent neurological testing? Detailed consideration of the preconditions for neurological testing. Were neurological tests conducted to confirm death? If not, why not? Was death confirmed using neurological criteria? If no, why not. Did the family observe the neurological testing?	✓ Brain death confirmed (Y/N) ✗ Specific details around the conditions for and circumstances of neurological death testing	The revised INICUA dataset will include the variable 'Were the criteria for neurological testing met?' This will be collected by the INICUA audit coordinator

NHSBT PDA dataset	NHS data variables	INICUA organ donation dataset ✓ Captured ✗ Unavailable	Comments
Donors after circulatory death	Was life-sustaining therapy withdrawn? Was imminent death anticipated by the medical staff? What did the life-sustaining treatment involve? If yes, what did the treatment withdrawal involve? If the patient was ventilated, what was the date and time of treatment withdrawal and asystole? What was the reason for the planned WLST? Were there DCD or infant donor exclusions? Was the patient considered suitable by the organ donation team following organ assessment?	✓ WLST ✗ Specific details around end-of-life care	
Patient donation decisions	What was the patient's last recorded NHS donor register status? When was the Organ Donor Register consulted? What was the reason the register was not consulted? Was permission from a coroner/procurator fiscal required/requested/granted? If no, why not for each element?	✓ Coroner permission ✗ Specific information for reasons for coroner refusal	Organ Donor Register currently not relevant but will be a legislative requirement in the future
Donation decisions conversation	Were the family asked to make or support an organ donation decision? If not, why not? Was the donation decision conversation discussed and planned with an organ donation personnel? When did it occur? Who was present (clinical/family/ODS team member(s)? What was the family reaction? Was consent/authorisation received from the family? If not, what were they reasons why? Were there previous donation conversations?	✓ Family approach (Y/N) ✗ Specific details of donation decision conversation and reasons for non-consent	
Outcome	Did solid organ donation occur? If no, why not? Did tissue donation occur? Eyes or other tissue? Reasons for non-donation outcome (n=34 reasons for non-donation outcome in addition to reasons patient not referred (n=15), reasons for consent not requested (n=7 reasons); reasons for family not asked to make decision (n=7); reasons conversation not as planned (n=8), reasons for no consent/authorisation (n=21)	✓ Organ donation outcome (Y/N) ✗ Granular detail on reasons for non-donation outcome and sequencing of events leading to missed opportunity	Tissue donation is not within the scope of this study. INICUA presents response option of 10 specific reasons for non-donation outcome

Approach to data collection

NHSBT data are collected by specialist nurses in organ donation during their normal working role in as close to real-time as possible. INICUA data are collected retrospectively by INICUA audit coordinators supported by Hospital Group ODNMs.

It may be feasible to retrospectively collect process data which are easily defined (i.e. Yes/No) or easily retrieved from medical records. Valid granular data requires prospective data collection by personnel closest to the process, as these data are often not retrievable from medical records. Thus, to ensure quality data, the INICUA dataset needs to be supported by ODNMs where possible due to their proximity to the process. Due consideration is required regarding the complexity and sensitivity of the data, e.g. end-of-life care processes and reasons why families do not donate; special expertise in organ donation is therefore required. ODP are best placed to understand the timing, nature, and sensitivities of the data.

Availability of reporting

Retrospective monthly and quarterly reports on organ donation can be provided by INICUA audit nurses upon request. The NHSBT dataset provides almost real-time data. This is important as the opportunities for organ donation are so few and every opportunity must be maximised.

4.4 IMPLICATIONS FOR THE FEASIBILITY STUDY

The INICUA dataset and the special focus on organ donation in the INICUA 2018 national report has been important in the development of organ donation audit in Ireland. It is the first dataset to provide data on organ donation practices in ICUs. At a high level, the INICUA dataset highlights the distribution of deaths across participating units, which may provide important information to inform resource allocation in organ donation. The feasibility study presents an opportunity to nurture the necessary relationships to support the INICUA dataset and ODP. Planned changes offer the potential for enhanced reporting to more closely align with the international data collections. The evaluation of such enhancements will be necessary over time. This is useful information but not comparable with NHSBT or other international PDA in terms of the approach to data collection and reporting.

Potential areas for improvement, including referral to ODP, DCD, and family assent, were identified in the INICUA annual report 2018 (National Office of Clinical Audit 2020). However, these findings may not be representative of the true situation as the potential donor pool is limited. The benchmarking of the INICUA against NHSBT identified limits to the extent to which the INICUA can drive improvement due to the high-level nature of data available, approach to data collection, and the timeliness of audit findings. The NHSBT PDA offers granular data across the entire organ donation process close to real-time, whereas the INICUA dataset does not allow targeted and timely feedback to ODP. It lacks valuable relevant detail on missed opportunities for organ donation and the granular detail required to drive improvement. A previous Irish national audit on organ donation using survey methodology identified that consent rates for organ donation were:

- 50%, where discussion was initiated by staff prior to brainstem testing
- 64%, when discussion of organ donation was initiated after completion of at least one brainstem test
- 80%, when initiated after diagnosis of brain death (Hegarty *et al.* 2010).

This information on family engagement, which highlights the timing and importance of sequencing of events, is not captured by the INICUA.

A PDA offers the possibility of widening the potential donor pool, identifying every missed opportunity, and providing the necessary and timely information to drive improvement across the entire organ donation process. Other settings, particularly ED, are of critical importance to the process of organ donation. The scope of the INICUA is limited to ICU, whereas the NHS PDA includes data collection in ED. Consulting with the INICUA organ donation data users on the value and use of current data would aid in the understanding of the relevance of the datasets.

CHAPTER 5

NATIONAL DATA COLLECTIONS



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CHAPTER 5: NATIONAL DATA COLLECTIONS

5.1 INTRODUCTION

This feasibility study identified national and local data collections currently available across the Irish health system that can provide information on the potential for organ donation. This high-level information is crude and merits closer exploration, but has potential to target improvement activities. This chapter describes relevant data collections and presents findings from national data collections on the potential for organ donation.

5.2 METHODOLOGY

Key thought leaders and subject matter experts were identified by the steering committee. Several virtual consultations took place to get a deep understanding of the available data. This yielded context and direction on available and potentially available data (see Appendix 2). Follow-up consultations were conducted as needed. Data requests were submitted to the Major Trauma Audit (MTA), Out of Hospital Cardiac Arrest Register (OHCAR), and Irish National Audit of Stroke (INAS), as it was considered that these national audits could provide meaningful information on the potential for organ donation.

5.3 FINDINGS

National and local data collections were identified, as outlined in Table 5.1. These data collections are fully described in Appendix 5. Their utility relevant to potential organ donation is described below. Information from the data collections is presented to illustrate the potential for organ donation in Ireland.

TABLE 5.1: DATA COLLECTIONS AVAILABLE IN IRELAND

National data collection	Local data collection
NOCA Irish National ICU Audit	Children's Health Ireland IntelliSpace Critical Care and Anaesthesia
NOCA Irish Paediatric Critical Care Audit	Potential Organ Donation Audit
NOCA Major Trauma Audit	
NOCA Irish National Audit of Stroke	
NOCA National Paediatric Mortality Register	
National University of Ireland Galway Out of Hospital Cardiac Arrest Register	
Central Statistics Office	

NATIONAL DATA COLLECTION

NOCA Irish National ICU Audit

This audit has been described in Chapter 4.

NOCA Irish Paediatric Critical Care Audit

The Irish Paediatric Critical Care Audit (IPCCA) was formerly the INICUA Paediatric Audit. In 2021, the IPCCA commenced limited data collection on organ donation using the PICANet (Paediatric Intensive Care Audit Network) dataset, which will produce outcome metrics in two specialised paediatric intensive care units in Children's Health Ireland (CHI) on:

- unit non-survivors
- solid organ donation (DCD and DBD).

This information is not available at time of writing this report.

NOCA Major Trauma Audit

Specific data variables relating to actual or potential organ donation are not collected in the MTA. However, the MTA provides valuable information to explore potential missed opportunities for organ donation. The MTA can provide high-level information on the number of patients with severe head injuries which are incompatible with life.

NOCA Irish National Audit of Stroke

Specific data variables relating to actual or potential organ donation are not collected in the INAS. However, the INAS can provide high-level information on patients with stroke. A small proportion of patients who die following a stroke may be offered the opportunity to become organ donors as part of their end-of-life care.

NOCA National Paediatric Mortality Register

Specific information on organ donation is not collected in the National Paediatric Mortality Register. Information on children who die in hospital and may be eligible to donate is available in other audits described in this chapter.

National University of Ireland Galway Out of Hospital Cardiac Arrest Register

Specific data variables relating to actual or potential organ donation are not collected in the OHCAR. However, the OHCAR provides valuable information on a cohort of people who die in Irish hospitals in circumstances that may be compatible with organ donation.

Central Statistics Office

The Central Statistics Office is pertinent in terms of deaths in Ireland. No specific information on organ donation is available, however. More information is available from current national clinical audits on specific information on in-hospital deaths.

LOCAL DATA COLLECTION

Children's Health Ireland IntelliSpace Critical Care and Anaesthesia

At CHI, data are continuously collected during patient care on the IntelliSpace Critical Care and Anaesthesia (ICCA) clinical information system (CIS) in Paediatric ICU (PICU). ICCA is available to clinicians at the patient's bedside.

At CHI Crumlin, data are collected on the potential for organ donation on customised forms on the CIS. These forms are based on two datasets:

- HSE Potential Donor Checklist Document
- PICANet.

This is not a data collection, rather a CIS designed to manage data in ICU and local healthcare professionals have adapted the system to capture data on organ donation. Data are collated for reporting locally as required.

At CHI Temple Street, data are collected at the bedside using ICCA in the PICU. The following variables are entered into the system:

- organ donation discussed (with family)
- organ donation discussed with coroner
- coroner's post-mortem
- hospital post-mortem
- referral to ODTI
- type of donation
- donation outcome (PICANet).

Potential Organ Donation Audit

Organ donor personnel (nurse managers and clinical leads) have started to carry out the Potential Organ Donation Audit, which is a local audit in the South/Southwest Hospital Group, University of Limerick Hospitals Group, Saolta Hospital Group, and the Royal College of Surgeons in Ireland (RCSI) Hospital Group, using a tool adapted from the NHSBT tool. Data are further analysed and reported locally. This information drives improvement in the participating hospital.

IMPROVEMENT CASE STUDY AT RCSI HOSPITAL GROUP USING THE NHSBT POTENTIAL DONOR AUDIT

**Karen Healy, Organ Donation Nurse Manager,
RCSI Hospital Group**



Background

I started in my role as an organ donation nurse manager at RCSI Hospital Group almost six years ago in 2015. This was a new role. Dr Alan Gaffney, RCSI Hospital Group Clinical Lead in Organ Donation, and I formed close links with our colleagues in Northern Ireland. We attended a few conferences in which they shared their data and results. Following this, we undertook the NHSBT PDA across two ICUs within the RCSI Hospital Group.

Area for improvement

In our units, we were interested in understanding the approach/assent conversation. The NHSBT PDA also allows us to see and understand:

- the timeframe from admission to when the brainstem tests are performed
- end-of-life care practices in the unit
- reasons why the patient who could undergo brainstem testing does not
- family assent – who is involved in the approach? Where is it being done? What are the reasons for ‘no assent’ among families?

It allows you to see if there is a pattern to families declining donation. Could it be that they are being asked too early or even being approached before they come to ICU? In April 2017, the audit clearly identified variability in practice between the two ICUs. Some of this variation in approach depended on the unit’s experience in brainstem testing.

Actions taken

With this information, we instigated programmes of change management and improvement in both units. The approach was based on international best practice that the family should not be approached until brainstem testing has been performed and decoupling the conversation around brainstem death and donation. This involved:

- Sharing audit findings with nursing, neurosurgical staff, and intensivists, which showed a pattern of assent to donation due to being approached when they have not dealt with the prognosis of their loved one.
- Encouraging the ICU to engage with ODP as early as possible in the process. This enabled the ODP to guide the unit staff on when to approach and be available to families to answer any questions or concerns they may have before they make a decision.
- Development of local algorithms or process flows to guide nursing staff if they have not been involved in this scenario before.
- Assigning the responsibility of family approach to the consultant intensivists only.

Now there is a culture of not approaching families until brainstem testing had been performed. Nurses no longer approach families at the bedside.

Conclusion

The NHSBT PDA has been beneficial in focusing specific areas for training and improvement. Continuing to audit practices highlights key areas for improvement. As a result, training and improvement can be tailored to that unit’s needs. As more Hospital Group personnel take on the PDA, we can benchmark our practices with other hospitals across the country. This will create a best practice standardised approach to care of the patient and their family undergoing the process of brainstem testing and potentially organ donation.

5.4 FINDINGS FROM DATA REQUESTS RELEVANT TO THIS FEASIBILITY STUDY

Major Trauma Audit

The purpose of this data request was to identify the number of patients admitted to hospital from 2014 to 2019 (inclusive) with a head injury that was incompatible with life. This patient cohort could potentially be offered the opportunity to become organ donors as part of their end-of-life care processes.

This information describes patients who:

- experienced significant head trauma, with an Abbreviated Injury Score 3–6¹ as the most injured body area
- died in hospital.

Data are presented on MTA data coverage, the volume of these patients, their age profile, and the location of their hospital stay. These data give an insight into the number of patients who died outside of ICU.

MTA data coverage

Data quality is a critical aspect of national clinical audit. Data coverage refers to the approved major trauma cases entered against the overall expected number of cases. Table 5.2 presents the MTA data coverage from 2014 to 2019. Data coverage refers to the approved major trauma cases entered against the overall expected number of cases. To achieve good-quality data for MTA, data coverage should be greater than 80% in hospitals. This is important to consider when making judgements about the data.

TABLE 5.2: MAJOR TRAUMA AUDIT COVERAGE, 2014-2019

Year	Coverage
2014	67%
2015	55%
2016	74%
2017	86%
2018	88%
2019	76%

Patients with severe head injuries who died in hospital

Following major trauma, 730 patients, who had a severe head injury (Abbreviated Injury Score ≥ 3) as their most injured body part, died in hospitals in the Republic of Ireland. The hospital level breakdown of patients is included in Appendix 5.

¹ Describes the severity of this head injury.

Age profile of patients

Patients included:

- 21 (3%) paediatric patients (≤ 15 years)
- 434 (59%) adults (16–79 years)
- 275 (38%) older adult patients (80 years and over). Patients over the age of 80 are less likely to be suitable for organ donation.

Location of stay

Forty-eight percent (n=354) of patients had no ICU stay.

Out of Hospital Cardiac Arrest Register

The purpose of this data request was to identify the number of patients admitted to hospital from 2015 to 2019 (inclusive) following an out-of-hospital cardiac arrest who subsequently died. Some of these patients could potentially be offered the opportunity to become organ donors as part of their end-of-life care processes.

This information describes patients:

- who were admitted to ED with return of spontaneous circulation (ROSC) who subsequently died
- who were admitted to ED with ongoing resuscitation who subsequently died.

Data are presented on OHCAR data coverage, the volume of patients, the age profile of these patients at hospital level, and the location in the hospital in which the patients died.

OHCAR data coverage

Table 5.3 presents the OHCAR data coverage from 2015 to 2019.

TABLE 5.3: OUT OF HOSPITAL CARDIAC ARREST REGISTER COVERAGE, 2015–2019

Year	Coverage
2015	100%
2016	100%
2017	100%
2018	100%
2019	100%

Patients admitted to hospitals in Ireland with out-of-hospital cardiac arrest

Following an out-of-hospital cardiac arrest, some 4,093 patients were admitted to hospital: 1,434 (35%) with ROSC and 2,659 (65%) with ongoing resuscitation. DCD pathways may make a small but meaningful contribution to the potential donor pool in the future. The hospital level breakdown of patients is included in Appendix 5.

Age profile of patients

Table 5.4 describes the age profile of patients who were admitted to hospital and subsequently died. The age profile of patients by hospital is presented in Table 5.4. While crude age categories were chosen, a more detailed age breakdown can be made available upon request from OHCAR Governance Committee.

TABLE 5.4: AGE PROFILE OF PATIENTS ADMITTED TO HOSPITAL WITH AN OUT-OF-HOSPITAL CARDIAC ARREST AND SUBSEQUENTLY DIED.

Age category	Patients admitted with ROSC (n=1434)	Patients admitted with ongoing resuscitation (n=2659)
Neonatal patients (0–28 days)	Neonates- Paediatrics* Total 18 (1%)	13 ($\leq 1\%$)
Paediatric patients (weeks to –15 years)		147 (6%)
Adult patients (16–79 years)	1101 (77%)	2001 (75%)
Older adult patients (80 years and over)	309 (22%)	455 (17%)
Incomplete data	6 ($< 1\%$)	43 (2%)

~ Denotes five cases or fewer.

* Further suppression required to prevent disclosure of five cases or fewer.

Location of death

Fifty-one percent (n=2084) of patients died in ED. Figure 5.1 presents the location of the hospital in which patients died by patient subgroup.

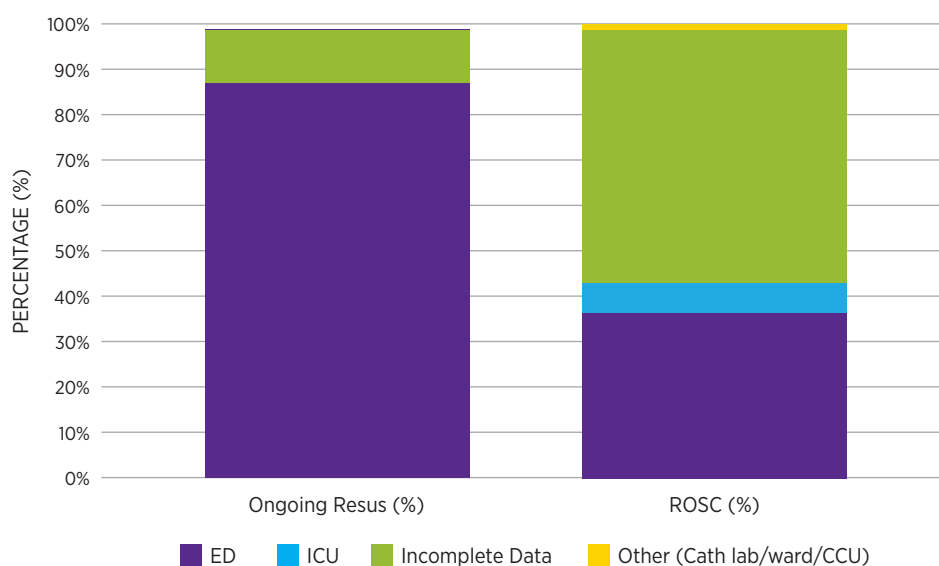


FIGURE 5.1: OUT-OF-HOSPITAL CARDIAC ARREST – LOCATION OF DEATH BY PATIENT SUBGROUP (2015–2019) (ARRIVED WITH ONGOING RESUSCITATION: n=2659; ARRIVED WITH RETURN OF SPONTANEOUS CIRCULATION: n=1434)

Irish National Audit of Stroke

The NOCA INAS Governance Committee was also asked to consider making data available that may be appropriate for the purposes of the feasibility study. The reported mortality rate for patients with a stroke in 2019 was 12% (n=508). When analysed by stroke type, the mortality rate was 9% (n=315) for patients with ischaemic stroke and 31% (n=193) for patients with haemorrhagic stroke, as reported in the INAS annual report in 2019. The PDA Feasibility Study Steering Committee was particularly interested in identifying those patients who may have received end-of-life care on the ward/ED following a stroke. However, the INAS Governance Committee deemed that this was not appropriate. The INAS does not collect the complete set of relevant information of interest to the PDA feasibility study and it was also commented that the primary focus of the INAS as it is currently configured is on stroke care and outcomes.

5.5 IMPLICATIONS FOR FEASIBILITY STUDY

1. Need for an audit to ensure improvement

Existing national audits, including the INICUA and IPCCCA, and local-level audits clearly highlight the need for a National PDA in the ICU. MTA and OHCAR identify activity that warrants further understanding in ED. The findings from this feasibility study do not include all deaths, particularly those with stroke, spontaneous intracranial haemorrhage, ischaemic stroke, and subarachnoid haemorrhage. Existing national audits may signal opportunities for improvement or donor activity to inform resource allocation. However, the current information does not provide the necessary information to drive improvement in organ donation.

Hospital-level findings likely reflect the size of the geographical catchment area, the patient profile served by the hospitals, and the prioritisation of out-of-hospital emergency care being brought to larger, more specialised hospitals, including neurosurgical units. Every hospital has a unique patient profile which needs to be understood in order to identify the true potential for organ donation. The patient profile may influence specific areas for improvement. The reconfiguration of trauma services will impact these distributions in the near future. Special consideration needs to be given to the characteristics of patients. There will therefore be a need for ongoing audit and improvement to reflect these changes and adjust clinical practice accordingly.

2. Support and ability for implementation of a national clinical audit

Local audits and quality improvement initiatives at Hospital Group level within Hospital Groups have demonstrated that there is a local need for more information that is standardised across sites and more granular in nature and that there is an opportunity to improve processes of care leading to organ donation. These audits also demonstrate support from front-line clinicians and the ability for implementation of a national clinical audit.

3. Need for a guideline to support improvements in clinical care

Not all patients who die following major trauma are suitable for organ donation. However, data explored for this PDA feasibility study identified patients with the most severe head injuries and thus the greatest likelihood of meeting the criteria for brainstem testing. Similarly, not all patients who die in hospital following OHCA are suitable for organ donation. National clinical guidelines are a valuable resource to guide and inform healthcare professionals and patient decisions about appropriate healthcare for specific clinical circumstances. This highlights the need for a national guideline on organ donation to ensure that these patients and their families are afforded the opportunity to consider organ donation.

4. Evidence for improvement

Depending on national laws, DCD and DBD might occur in up to 5–10% of non-survivors following cardiac arrest (Perkins *et al.* 2021). More than 40% of these patients could donate organs (Sandroni *et al.* 2016). If a patient achieves ROSC following OHCA, it is likely that they would be eligible for admission to ICU for further stabilisation and management, and, depending on their clinical outcome, become a potential organ donor. A patient receiving continuing resuscitation may not be stable enough for admission to ICU. Currently, there is no donation pathway directly from ED to the operating theatre in Ireland, but it may be possible to facilitate this in the future in some centres with the appropriate infrastructure (e.g. clinical guidelines, laboratory support, ODP, normothermic regional perfusion, and ethical approval for uncontrolled DCD). A deeper understanding of end-of-life care practices – in both ED and ICU – would give a more accurate understanding of the potential for organ donation in this population and drive improvement.

In conclusion, a number of national audits provide high-level information on people who die in Irish hospitals. These data may be useful to inform service planning and resource allocation. The findings of the feasibility study highlight areas that warrant deeper exploration, particularly in ED. The national audits lack specific information on the nature and circumstances of patient deaths and their end-of-life care processes. These findings highlight the need for a specific PDA to accurately determine the potential donor pool and provide the necessary granular information to drive improvement. Local-level audits demonstrate the drive to fill this gap in data and demonstrate front-line capacity and support for this approach.

CHAPTER 6 **STAKEHOLDER SURVEY**



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CHAPTER 6: STAKEHOLDER SURVEY

6.1 INTRODUCTION

An online survey was conducted to evaluate the perceived value of existing Irish data and to explore what additional data are required to drive improvement in organ donation.

The objectives of the survey were as follows:

- describe the perceived level of importance of existing data in driving improvement
- make suggestions for additional data that would drive improvement
- explore current use of data from the INICUA
- identify any barriers to using the INICUA.

6.2 METHODOLOGY

ODP and ODTI administration were identified as the most relevant data users for organ donation data. All relevant personnel were invited to participate in the survey (see Appendix 6), as follows:

- Six Hospital Group clinical leads in organ donation (CLODs)
- Six Hospital Group organ donation nurse managers (ODNMs)
- The National Organ Procurement Service (NOPS) – eight clinical nurse managers and one assistant director of nursing, and one NOPS quality manager
- Three executive staff from ODTI (chief operations officer, quality manager, director).

Of all those considered to participate, it was known that two ODNM positions were unfilled at the time of the survey, giving a total possible response of 23. Members of the steering committee representing the nominated groups above were consulted to provide additional depth and clarity to the findings of the survey.

6.3 FINDINGS

Response rate

Twenty-three respondents completed the survey, giving a response rate of 100%.

Perceived importance and use of existing data

- Most respondents (71.4%, n=15/21 to 100%, n=19/21) reported that existing data variables described in Chapter 5 were important or very important depending on which variable was assessed (see Appendix 6, section 3).
- There was incomplete uptake (self-reported reading) of the following existing national reports (see Table 6.1)

TABLE 6.1: UPTAKE OF EXISTING NATIONAL REPORTS

Report	Percentage (%) (n)
INICUA 2018 National Report	57% (13/23)
INICUA 2019 National Report	35% (8/23)
OHCAR National Report 2018 or 2019	17% (4/23)
201 MTA 2018 or 2019	43% (10/23)

- Only three respondents reported accessing INICUA database reports for their unit often or very often. This represents 33% (3/10) of current ODP at hospital level. ODP are the only relevant personnel for this hospital-level data

Additional data which may be useful

Respondents identified three additional categories of data that would facilitate the identification of missed opportunities for organ donation.

Detecting the potential donor pool

- The number of patients who died with acute cerebral lesions
- The number of patients who were potentially brain dead
- A breakdown of DCD by age +/- 60 years

Granular information

- Information surrounding the family approach – was it planned/who was present/where/when?
- Reasons – reasons why relevant patients were not brainstem tested; reasons why family was not approached; very specific reasons for non-donation outcome.
- Timings of processes – time from admission to family approach; time from referral to NOPS personnel to decision; time from referral to the operating theatre.

Barriers to using the INICUA

The following barriers to using the INICUA to drive quality improvement were identified:

- not capturing patients who are potentially brain dead
- specificity and granularity of data to drive learning and improvement
- access/reporting.

Further targeted consultation with ODP provided greater depth and clarity surrounding these barriers.

Not capturing patients who are potentially brain dead

Not capturing patients who are potentially brain dead was identified as a significant barrier to using the INICUA – thus, not quantifying the potential donor pool and therefore all eligible donors. It was acknowledged that capturing those who were potentially brain dead would increase the total theoretical maximum potential donor pool. If a greater number of patients were brainstem tested, this may lead to improved opportunities for organ donation and improved number and quality of organs available for donation. Furthermore, including ED and patients who die following stroke was highlighted as important.

Specificity and granularity of data to drive learning and improvement

ODP highlighted that greater specificity and granularity of data is required to provide detailed information about the processes of identifying potential donors, the management of the potential donor at the end-of-life, and communication with the potential donor family. They felt that the people best placed to collect data are the specially trained ODP, who are closest to the process and understand the nature and context of the processes and conversations that take place, which form the basis of the data. This type of data is either complex (e.g. practices to assess criteria for brainstem testing), sensitive, or qualitative (e.g. reasons why families do not donate). These data are often not documented in medical records and thus not practicable to obtain accurately retrospectively. ODP felt that these data need to be collected during the process by ODP in as close to real-time as possible.

Access/Reporting

There were a number of responses identified in the open responses to the survey around the concept of access. It was not clear precisely what was meant by this or by whom. As this is hospital-level information, it is intended that only Hospital Group ODP have access to hospital data.

It was identified in the follow-up consultations that the opportunities for organ donation were so few that almost real-time access to data and reporting is required to empower ODP to drive improvement and address any individual or system issues that may hamper the efforts of ODP. It was felt that quarterly or annual reporting would be too late to maximise opportunities to drive improvement in organ donation rates.

6.4 IMPLICATIONS FOR THE FEASIBILITY STUDY

This survey highlights the perceived value of existing high-level data in Ireland. While the existing national data are informative, from a data quality perspective they are not relevant to current or future needs of the ODP community (Health Information and Quality Authority 2018). Engagement with the relevant data users highlights that data should identify a broader, more specific donor pool and requires context and granularity to make it meaningful and valuable in driving improvement. The addition of specific detailed data that are validated and reported on quickly is required to promptly address the reasons for missed opportunities in organ donation.

The background of the page is a blurred photograph of a hallway. In the foreground, a person in a blue uniform is walking away from the camera. In the background, another person in a white uniform is walking towards the camera. The hallway has a light-colored floor and walls, and there are bright lights on the ceiling.

CHAPTER 7

RECOMMENDATIONS

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CHAPTER 7: RECOMMENDATIONS

The aim of this feasibility study was to develop an options appraisal for a National PDA. There is an urgent need for a PDA to ensure compliance with the EU Council Directive 2010/45/EU and Statutory Instrument (SI) No. 325 of 2012 requirement for data collection for publication annually in relation to organ donation and to ensure compliance with the imminent legislation for an organ donation register through the Human Tissue (Transplantation, Post-Mortem, Anatomical Examination, and Public Display) Bill 2018 (Department of Health 2020), which includes a soft opt-out consent.

Following international and local consultation, benchmarking of national data and a survey of organ donation data users, a virtual world café-style workshop was held. The steering committee considered the findings of this feasibility study and identified the recommendations from this work. Three possible recommendations were discussed and voted upon. There was consensus to put forward two recommendations:

1. Develop a national PDA within one year:
 - Implement a PDA in Ireland: Implement the PDA in one hospital in six hospital groups prior to expanding the implementation to all acute hospitals, including paediatric hospitals as organ donation nurse manager (ODNM) resources increase.
 - In parallel, develop national guidelines on the organ donation process.
2. Use existing national audits to highlight potential organ donors across the hospital system, as an interim measure:
 - In parallel with the roll-out of a National PDA, and until the PDA is operational in all acute hospitals, use reporting from existing national audits to highlight potential organ donation opportunities across the hospital system.
 - The INICUA includes information on potential donor activity.
 - Exploring the rates and distribution of deaths from INICUA, IPCCA, MTA, OHCAR, and other national data collections may inform resource allocation over time.

Table 7.1 and Table 7.2 detail who benefits from the recommendations, who owns the action, what action should be taken, prioritisation, rationale, and evidence base for each recommendation. The rationale considers the feasibility study findings and potential consequences should no change occur. Where there is a recommendation for a national clinical audit, this rationale is presented using the criteria for prioritisation of national clinical audit (National Clinical Effectiveness Committee 2015). Recommendations are based on cited evidence, indicating that their implementation will lead to improvement. The costs of Recommendation 1 are included in Appendix 7.

TABLE 7.1: RECOMMENDATION 1: DEVELOP A NATIONAL POTENTIAL DONOR AUDIT

RECOMMENDATION 1
<p>Develop a National PDA within one year:</p> <ul style="list-style-type: none"> • Implement a PDA in Ireland – implement the PDA in one hospital in six hospital groups prior to expanding the implementation to all acute hospitals, including paediatric hospitals as ODNM resources increase. • In parallel, develop national guidelines on the organ donation process.
Who benefits from the recommendation?
<ul style="list-style-type: none"> • Patients who want to become organ donors should they find themselves in the position where organ donation is a possibility. • Families who obtain assurance and condolence that their loved ones have the opportunity to donate their organs should this be their wish and who experience enhanced quality of care around donation conversations. • Healthcare staff who have a better understanding of where the process of organ donation can be improved. • Health service providers who can ensure that all donors can be given the opportunity to donate organs where this was their wish. • Legislators – in the future, this national audit can provide annual information which is publicly available and an assurance of the legislative requirement to check the organ donation register (EU Council Directive 2010/45/ EU ; Statutory Instrument (S.I) No. 325 of 2012. ; Department of Health 2020). • Patients with end-stage organ failure who are awaiting an organ transplant.
Who leads this action?
<p>(a) NOCA and ODTI</p> <p>(b) Intensive Care Society of Ireland (ICSI)</p>
What action should be taken?
<ul style="list-style-type: none"> • NOCA and ODTI to take the following steps to develop a National PDA: <ul style="list-style-type: none"> - Present a proposal for initial and subsequent phases to stakeholders, Department of Health and the HSE National Steering Group for Clinical Audit, to seek approval and funding for audit implementation. - Instigate an audit development phase in NOCA under a steering committee. This includes definition and testing of dataset, review ethical framework for audit, development and pilot testing of audit methods – data sources, data collection, cleaning, validation, analysis and reporting, public engagement and consultation, development of an information governance framework. Assessment of an IT (information technology) system infrastructure for a PDA should include both national and international partners, with a recommendation for local development or collaboration with an international partner. Important criteria guiding this include capacity and timelines of implementation. • ICSI to lead the development of a guideline for the organ donation process in consultation with stakeholders: <ul style="list-style-type: none"> - Form a steering committee to support this guideline development.

Prioritisation

1 year

Rationale for this recommendation

Burden of this topic

- Rates of organ donation are 18 pmp compared to 25 pmp in the UK and in excess of 45 pmp in Spain. This illustrates a need and opportunity to improve (see Chapters 1 and 3).
- The international need for organs has persistently outstripped supply.
- Every year people die while awaiting transplantation (ODTI, 2020).

Need for an audit to ensure improvement

- There are insufficient data on deaths available in Ireland to measure a true baseline in the organ donation processes or to drive improvement. This is particularly true for ED (see Chapters 4 and 5).
- Detailed analyses of all deaths in ICU and ED provide meaningful, reliable surveillance data that are suitable for annual and international benchmarking and for driving improvement (see Chapters 3, 4, 5).
- Leading countries in organ donation collect granular process data. These data are required to empower ODP to drive improvement locally (see Chapter 3).
- Existing national data do not provide the necessary information to drive improvement (see Chapters 3, 4, 5, 6).

Variability in current practice on organ donation

- There is consistent evidence that at every stage of the clinical pathway opportunities for DBD and DCD are lost in all European member states and the UK (European Commission 2009).
- There is significant variability in all aspects of the patient pathway, including intubation and ventilation, brain death testing, brain death confirmation, DCD donation, referral to key donation personnel, the family approach, and actual donation (European Commission. 2015; National Office of Clinical Audit 2020).

Support and ability for implementation of a national clinical audit

- This recommendation has strong support from the Potential Donor Audit Feasibility Study Steering Committee, including stakeholder groups: ODTI, ODP, Irish Association of Critical Care Nurses, Irish Association for Emergency Medicine, ICSI, Strange Boat Donor Foundation, patient and public interest representatives.

Need for a guideline to support improvements in clinical care

- There are no comprehensive Irish national guidelines to govern the complete organ donation process.

Evidence base for implementation

Evidence for improvement in organ donation

- Clinical audit and quality improvement are key factors in the success of the world leader in organ donation rates (see Chapter 3).
- There has been continuous improvement in five-year trends for key numbers and rates (see Chapter 3).
- The opportunities for identifying missed donor potential are so few that reporting is required in almost real-time where quality improvement initiatives can be made (see Chapter 5). The example from NHSBT supports this approach.
- Specific detailed information about processes of care and reasons for missed opportunities are a priority for members of the feasibility study steering committee (see Chapter 5).

Evidence on the impact of guidelines

- International guidelines exist for the organ donation process. This recommendation will lead to the development of specific national clinical guidelines against which care can be measured (see Chapter 3).
- There is strong evidence of improvement in donation rates as a result of the implementation of guidelines (Matesanz *et al.* 2012).

TABLE 7.2: RECOMMENDATION 2: USE EXISTING NATIONAL AUDITS TO HIGHLIGHT POTENTIAL ORGAN DONORS ACROSS THE HOSPITAL SYSTEM, AS AN INTERIM MEASURE

RECOMMENDATION 2

In parallel with the roll-out of a National PDA, and until the PDA is operational in all acute hospitals, use reporting from existing national audits to highlight potential organ donors across the hospital system.

The INICUA includes information on potential donor activity as will the IPCCA. Exploring the data from the INICUA, IPCCA, MTA, OHCAR, and other national clinical audits may inform resource allocation over time.

Who benefits from the recommendation?

- Health service providers – who obtain valuable high-level information to inform resource allocation by highlighting areas of increased potential donor activity.
- Health service providers – who obtain assurance around the value of their investment in existing national data that can be mobilised for efficiencies of healthcare.

Who leads this action?

ODP and ODTI

What action should be taken?

Coordination between ODNMs and the INICUA

- ODNMs will continue to work closely with INICUA audit coordinators to ensure quality data to support organ donation in Ireland (see Appendix 4).
- ODTI will seek national annual reports from INICUA, IPCCA, MTA, and OHCAR or other audits to examine potential donor possibilities. These reports will be disseminated to Hospital Group ODP. This information can inform resource allocation and service planning for subsequent phases of the National PDA.

Prioritisation

1 year

Rationale for this recommendation**Current availability of information until the PDA is operational**

- There are a number of national clinical audits with data identified as important/very important to ODP (see Chapter 5).
- This recommendation is appropriate as relevant data exist which points towards the potential organ donor pool both within and outside ICU.
- Existing national data collections on deaths may inform resource allocation and offer a unique opportunity for improvement
(Elmer *et al.* 2021; Fu Wah Ho *et al.* 2021).

Need to identify opportunities for improvement until the PDA is operational

- There is evidence of opportunity for improvement in the DCD pathway (National Office of Clinical Audit 2020; Global Observatory on Donation and Transplantation 2021). OHCAR and MTA data suggest that there may be potential for improving donation through the DCD pathway in the context of decision to WLST in ED (see Chapter 4).

Evidence base for implementation**Evidence from other jurisdictions**

- Other jurisdictions explore high-level information around deaths in ICU to monitor the theoretical potential donor pool (e.g. Italy) (see Chapter 3).
- OHCAR data in other countries have identified a small but significant unrealised pool of DCD donors among out-of-hospital cardiac arrest cases (see Chapter 4).

CHAPTER 8

CONCLUSION



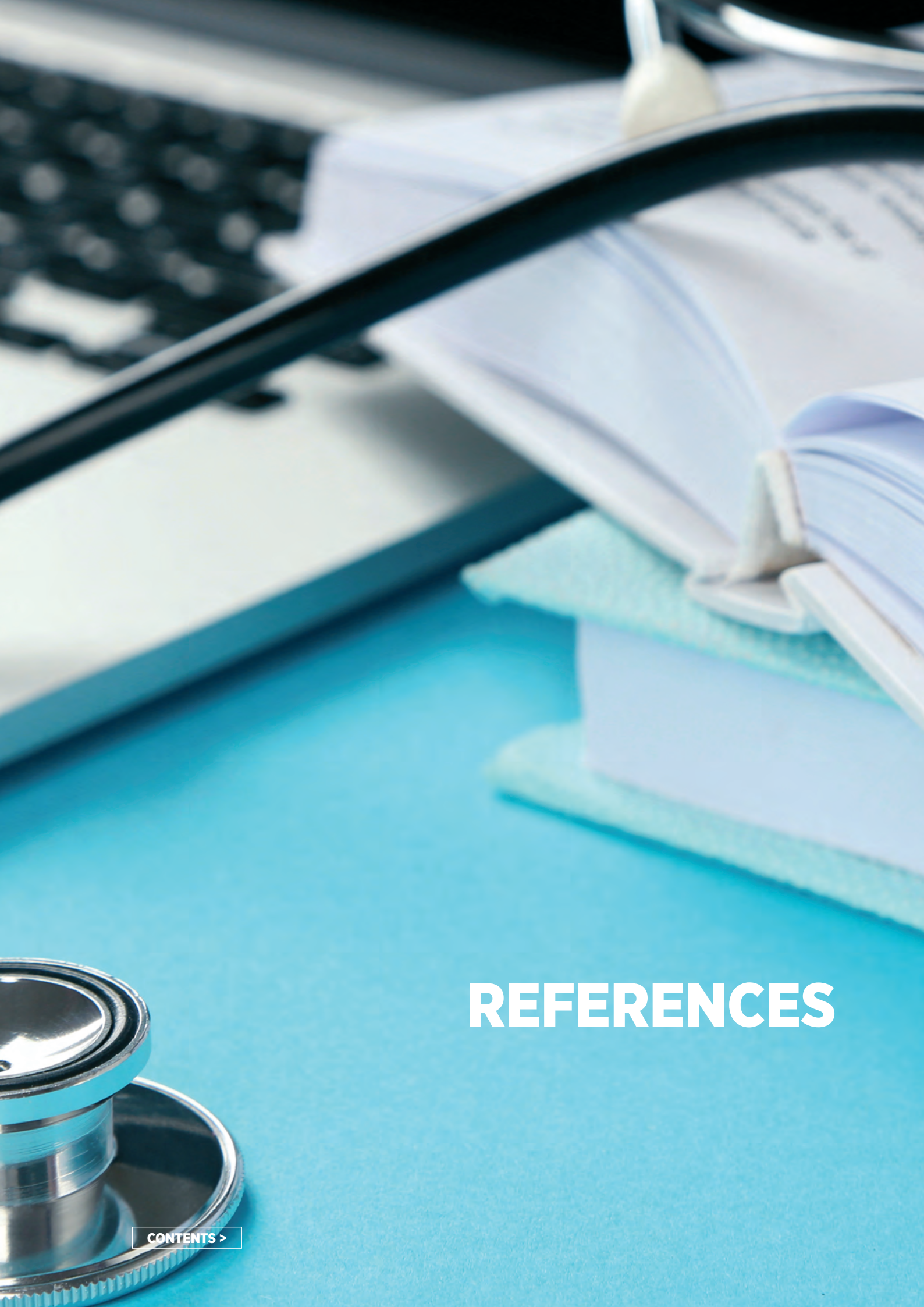
CHAPTER 8: CONCLUSION

This study clearly identifies the information that is needed by ODP to support their work and to drive improvement in organ donation. This feasibility study builds on previous work to recommend development of a new National PDA. Evidence suggests that this recommendation can identify all missed opportunities for organ donation and empower ODP with the necessary information to drive improvement. There is an urgent need to implement this recommendation to ensure that:

- Every person whose death is compatible with organ donation is afforded the possibility of organ donation should that be their wish.
- The legislative requirements to provide information on organ donation are met.
- The healthcare community have information that they require to identify missed opportunities and drive improvement.
- Information is available to public groups to account for donor rates in Ireland.

Existing national data can be used to inform resource allocation to expedite the national roll-out to all hospitals.

The process of this study has revealed that there is less awareness of organ donation practices outside of ICU. A national guideline will go some way to enhancing understanding across the hospital community. Early engagement with relevant stakeholders will be crucial for implementation of a new national guideline.



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APPENDICES



APPENDIX 1: STEERING COMMITTEE MEMBERSHIP AND ATTENDANCE AT MEETINGS

TABLE A1.1: POTENTIAL DONOR AUDIT FEASIBILITY STUDY STEERING COMMITTEE MEMBERSHIP AND ATTENDANCE AT MEETINGS

Organisation	Role	Name	Meeting 1	Meeting 2	Meeting 3
HSE National Quality Improvement Team	Chair	Dr Philip Crowley	✓	✓	✓
HSE Hospital Groups Clinical Lead in Organ Donation	Clinical Lead – Feasibility study; Clinical Lead Organ Donation, RCSI Hospital Group; Consultant Intensivist, Beaumont Hospital	Dr Alan Gaffney	✓	✓	✓
HSE Acute Operations	General Manager, HSE Acute Operations	Trina Doran	✓		
HSE Hospital Groups	Organ Donation Nurse Manager	Karen Healy	✓	✓	✓
Intensive Care Society of Ireland	President	Dr Colman O'Loughlin	✓	-	✓
Irish Association of Critical Care Nurses	ICU Nurse	Breda Doyle	✓	✓	-
Member of public	Patient and Public Interest Representative	Louise Galvin	✓	-	✓
Strange Boat Donor Foundation	Patient and Public Interest Representative	Martina Goggin	✓	✓	✓
NOCA	Head of Quality and Development	Marina Cronin	✓	✓	✓
NOCA	Postdoctoral Researcher	Dr Maria Kehoe, PhD	✓	✓	✓
NOCA	INICU Audit Manager	Mary Baggot	-	-	✓
NOCA	INICUA Clinical Lead	Dr Rory Dwyer	✓	-	-
ODTI	National Organ Procurement Service	Caroline Lynch April–July 2021	✓		
		Emma Corrigan July 2021–October 2021		✓	✓
ODTI	Chief Operations Officer	John Walsh	✓	✓	✓
ODTI	Director ODTI; Consultant Lung Transplant Physician, Mater Misericordiae University Hospital	Prof. Jim Egan	✓	✓	✓
ODTI	Quality Manager, National Organ Procurement Service	Hilary Barry	✓	✓	-
Irish Association of Emergency Medicine	Consultant in Emergency Medicine Cork University Hospital; Clinical Lead for Organ Donation, South/Southwest Hospital Group	Dr Adrian Murphy	✓	✓	-
Children's Health Ireland	Consultant Paediatric Intensivist, Crumlin	Dr Suzanne Crowe	✓	✓	-
National Clinical Programme for Stroke	Clinical Lead	Prof. Rónán Collins	-	-	-

APPENDIX 2: LIST OF CONSULTATIONS

TABLE A2.1: LIST OF CONSULTATIONS

Consultation	Role	Organisation
John Walsh	Chief Operations Officer, ODTI	ODTI
Karen Healy	Organ Donation Nurse Manager	RCSI Hospital Group
Mary Baggot	INICUA Manager	NOCA
John Walsh, Caroline Lynch, Trina Doran	ODTI	ODTI
Carol Anne Hennessy	Central Statistics Office	Central Statistics Office
Dr Alan Gaffney	Clinical Lead of the feasibility study	RCSI Hospital Group
Caroline Lynch	National Organ Procurement, Acting Director of Nursing	ODTI
Hilary Barry	ODTI Quality Manager	ODTI
Prof. Jim Egan	Director ODTI	ODTI
Dr Michael O’Leary	Co-State Medical Director, New South Wales Organ and Tissue Donation Service (Australia)	NSW Organ and Tissue Donation Service (Australia)
Breda Doyle	ODNM South/Southwest Hospital Group	Irish Association of Critical Care Nurses
Charlotte Carter	ICU Clinical Nurse Manager	Portiuncula University Hospital
Dr Julien Charpentier	Clinical Lead for Organ Donation Paris (France)	Assistance Publique – Hôpitaux de Paris (AP-HP) Centre, Université de Paris
Dr Francesco Procaccio	Clinical Lead for Organ Donation Rome (Italy)	Italian National Transplant Centre, Italian National Institute of Health, Rome, Italy
Elizabeth Kenny	ICU Clinical Nurse Manager	Cavan Hospital
Bridget Doyle	ICU Clinical Nurse Manager	Cork University Hospital
Dr Helen Odpm and Mark McDonald	National Medical Director and National Manager Analytics and Technology, Australian Organ and Tissue Authority	Australian Organ and Tissue Authority
Trina Doran	General Manager, HSE Acute Operations	HSE Acute Operations
Dr Suzanne Crowe	Consultant Paediatrician, CHI Crumlin	CHI at Crumlin
Dr Cliona McGarvey, PhD	Paediatric Programme Manager, NOCA	NOCA
Monica Hackett, Laura-Ellis Morgan, Mary McAfee	Regional Manager (NI), Head of Health Informatics for the Directorate (UK) and Specialist Nurse in Organ Donation (NI)	NHSBT

Consultation	Role	Organisation
Paul Hendrick	ODTI Quality Manager	ODTI
Dr Rory Dwyer	Audit Clinical Lead, INICUA	INICUA
Dr Conor Deasy, Mr Martin Quinn, Siobhan Masterson	Clinical Lead, Audit Manager, National Ambulance Service Lead for Clinical Strategy and Evaluation, Out of Hospital Cardiac Arrest Register	Out of Hospital Cardiac Arrest Register
Dr Colman O'Loughlin	President, Intensive Care Society of Ireland	Intensive Care Society of Ireland
Louise Brent	MTA Manager	NOCA
Susanna Madden	Principal Statistician, Statistics and Clinical Research, NHSBT	NHSBT
Ruth Joyce	Blood, Tissues and Organs Manager, Health Products Regulatory Authority	Health Products Regulatory Authority
Dr Michael Barrett	Paediatric Consultant in Emergency Medicine, CHI at Crumlin, Clinical Lead, National Paediatric Mortality Register	CHI at Crumlin
Prof John Murphy	Consultant Neonatologist National Maternity Hospital, Dublin; Clinical Lead, National Clinical Programme for Paediatrics and Neonatology	National Clinical Programme for Paediatrics and Neonatology
Dr Gloria de la Rosa	Medica Adjuncta, Organización Nacional de Trasplantes (Spain)	Organización Nacional de Trasplantes
Prof. Rónán Collins	Clinical Lead, National Clinical Programme for Stroke	National Clinical Programme for Stroke
Joan McCormack	INAS Manager	NOCA
Emma Corrigan	Donor Coordinator	ODTI
Dr Alex Manara	Consultant in Intensive Care Medicine at Southmead Hospital, North Bristol NHS Trust, Bristol, UK	NHSBT
Erika Brereton	Audit Coordinator and Data Manager	CHI at Crumlin
Marie Lawlor	PICU Audit Coordinator	CHI at Temple Street
Margo Dunworth	National Neonatal Resuscitation Programme Coordinator	National Women and Infants Health Programme
Dr Michael O'Connor	National Clinical Advisor and Group Lead, Acute Operations	HSE Acute Operations

APPENDIX 3: RATES OF ORGAN DONATION IN COUNTRIES INCLUDED IN THE FEASIBILITY STUDY

TABLE A3.1: RATES OF ORGAN DONATION OVER TIME, PER MILLION POPULATION, 2015–2019

Country	2015	2016	2017	2017	2019
Ireland	17.7	16.2	20.8	17.1	17.4
UK	20.2	21.4	23.1	24.5	25.9
Spain	39.7	43.4	46.9	48.0	49.6
France	28.1	28.7	29.7	28.9	33.3
Italy	22.5	24.3	28.2	24.6	24.7
Australia	18.3	20.8	20.7	22.2	21.6

Source: Global Observatory on Donation and Transplantation (2021)

APPENDIX 4: IRISH NATIONAL ICU AUDIT

DATA ACCESS

- A request form needs to be completed for each hospital within a Hospital Group.
- Following approval by hospital management, INICUA audit nurses in the relevant site can download the pre-formatted organ donation report (Report 15) on a quarterly basis.
- ODP can use the INICUA reports throughout the Hospital Groups to identify areas for improvement.
- Further information is available on request through the NOCA INICUA audit manager: auditinfo@noca.ie

ODNM AND INICUA AUDIT NURSES

ODNMs work with INICUA audit coordinators on all units in their Hospital Group to ensure quality data to support organ donation in Ireland. This should involve:

- provision of training from the INICUA audit manager to ODNMs to improve the ODNM's understanding of the INICUA dataset
- cross-checking of data between INICUA audit nurses and the Hospital Group ODNM.

APPENDIX 5: NATIONAL DATA COLLECTIONS

DESCRIPTION OF DATA COLLECTIONS

NOCA Irish Paediatric Critical Care Audit

The Paediatric Intensive Care Audit Network (PICANet) audit commenced in two specialised paediatric intensive care units in Children's Health Ireland (CHI) in 2010 and transitioned to the governance structures of NOCA in February 2013. NOCA works with PICANet to deliver this audit to paediatric units. This audit, now called the Irish Paediatric Critical Care Audit (IPCCA), has expanded to include information on children cared for in adult regional units as well as a single regional high-dependency unit. It issued its first national report in 2021. The NOCA INICUA Governance Committee governs the output from IPCCA, producing national reports. Participating units in hospitals are responsible for reviewing and using reports for quality assurance and improvement.

The IPCCA aims to improve critical care services provided to patients by measuring the quality of care and outcomes against agreed clinical standards. The units report on activity using quality indicators that are benchmarked against other participating units across Ireland and the UK.

NOCA Major Trauma Audit

In 2013, the Major Trauma Audit (MTA) was set up in NOCA using the Trauma Audit Research Network methodology. The focus of this audit is to capture data on the injured trauma patients. NOCA provides governance for this audit and the MTA Governance Committee comprises both clinical and non-clinical stakeholders with an interest in trauma care. As with other NOCA audits, participating hospitals submit data which is analysed and reported back. Participating hospitals are responsible for reviewing and using reports for quality assurance and improvement.

NOCA Irish National Audit of Stroke

The National Stroke Register was established in 2011 and transitioned into the governance structures of NOCA as Irish National Audit of Stroke (INAS) in 2019. INAS collects high-quality data for the purpose of healthcare quality improvement. NOCA provides governance for this audit and the INAS Governance Committee comprises both clinical and non-clinical stakeholders with an interest in stroke care. As with other NOCA audits, participating hospitals submit data which is analysed and reported back. Participating hospitals are responsible for reviewing and using reports for quality assurance and improvement.

NOCA National Paediatric Mortality Register

The National Paediatric Mortality Register, established in 2010, transitioned to NOCA in October 2020. This register is a centralised national system for collection and analysis of data relating to mortality in the Irish paediatric and adolescent population (<16 years) both in the community and in hospital, which provides for development of policy and intervention strategy.

National University of Ireland Galway Out of Hospital Cardiac Arrest Register

The Out of Hospital Cardiac Arrest Register (OHCAR) is jointly managed by the Department of General Practice, National University of Ireland Galway and the HSE. OHCAR collects data on out-of-hospital cardiac arrests in Ireland, which are confirmed and attended by the Emergency Medical Services and where resuscitation is attempted. Data are collected from the pre-hospital emergency services in Ireland and patient outcome information is sourced from acute hospitals. An annual report is published.

Central Statistics Office

Statistics on deaths registered in Ireland have been collected and published since 1864. This was initially carried out by the General Register Office. Since 1953, the reports have been compiled by the Central Statistics Office, based on administrative data supplied by the General Register Office. They provide a comprehensive picture of the number of deaths, ages at death, and underlying causes of death of the population.

Data are captured by the attending medical practitioner, and in the case of unexpected deaths or deaths due to external causes, the cause of death is determined by the coroner, following a post-mortem and possibly an inquest. This information is entered electronically at registry offices around the country and sent to the General Register Office. All deaths occurring in Ireland are legally obliged to be registered (there are approximately 30,000 deaths annually). Non-registration is rare but there can sometimes be considerable delay in registration of deaths, particularly in the case of deaths requiring an inquest.

FINDINGS FROM DATA REQUESTS

Major Trauma Audit

TABLE A5.1: PERCENTAGE OF PATIENTS WHO DIED IN HOSPITAL FOLLOWING A SEVERE HEAD INJURY AS THEIR MOST INJURED BODY PART (n=730), BY HOSPITAL SITE

Site	Number (n)	Percentage (%)
Beaumont Hospital	157	22%
Cork University Hospital	135	18%
St Vincent's University Hospital	53	7%
Our Lady of Lourdes Hospital, Drogheda	46	6%
Connolly Hospital Blanchardstown	45	6%
University Hospital Galway and Merlin Park University Hospital	35	5%
Mater Misericordiae University Hospital	32	4%
University Hospital Limerick	29	4%
Cavan General Hospital	23	3%
University Hospital Kerry	23	3%
St James's Hospital, Dublin	20	3%
Tallaght University Hospital	20	3%
South Tipperary General Hospital	14	2%
St Luke's General Hospital, Carlow/Kilkenny	13	2%
Mayo University Hospital	12	2%
Wexford General Hospital	12	2%
Naas General Hospital	11	2%
University Hospital Waterford	10	1%
CHI at Temple Street	9	1%
Sligo University Hospital	7	1%
Mercy University Hospital	6	1%
Midland Regional Hospital Tullamore	6	1%
Letterkenny University Hospital	~	*
Midland Regional Hospital Mullingar	~	*
Midland Regional Hospital Portlaoise	~	~
Total	730	100%

~ Denotes five cases or fewer.

* Further suppression required to prevent disclosure of five cases or fewer.

TABLE A5.2: PATIENTS ADMITTED TO HOSPITAL FOLLOWING OUT-OF-HOSPITAL CARDIAC ARREST, BY LOCATION AND OUT-OF-HOSPITAL CARDIAC ARREST PATIENT SUBTYPE (n=4093)

Site	Total (n)	Percentage (%)	ROSC (n)	Percentage (%)	Ongoing Resuscitation (n)	Percentage (%)
Cork University Hospital (CUH)	371	9%	182	49%	189	51%
St James's Hospital	356	9%	110	31%	246	69%
University Hospital Limerick	300	7%	118	39%	182	61%
Mater Misericordiae University Hospital	299	7%	78	26%	221	74%
Beaumont Hospital	297	7%	85	29%	212	71%
St Vincent's University Hospital	242	6%	118	49%	124	51%
Tallaght University Hospital	242	6%	67	28%	175	72%
University Hospital Galway and Merlin Park University Hospital	237	6%	73	31%	164	69%
Connolly Hospital Blanchardstown	230	6%	61	27%	169	73%
Our Lady of Lourdes Hospital, Drogheda	157	4%	57	36%	100	64%
University Hospital Waterford	130	3%	35	27%	95	73%
University Hospital Kerry	113	3%	48	42%	65	58%
Naas General Hospital	107	3%	41	38%	66	62%
St Luke's General Hospital, Carlow/Kilkenny	102	2%	47	46%	55	54%
University Hospital Sligo	94	2%	41	44%	53	56%
South Tipperary General Hospital	87	2%	32	37%	55	63%
Mercy University Hospital	85	2%	30	35%	55	65%
Letterkenny University Hospital	75	2%	24	32%	51	68%
Portiuncula University Hospital	71	2%	28	39%	43	61%
Wexford General Hospital	71	2%	22	31%	49	69%
Midland Regional Hospital Portlaoise	67	2%	24	36%	43	64%
Cavan General Hospital	64	2%	13	20%	51	80%
Mayo General Hospital	62	2%	24	39%	38	61%
Midland Regional Hospital Mullingar	60	1%	21	35%	39	65%
Our Lady's Hospital Navan	59	1%	23	39%	36	61%
Midland Regional Hospital Tullamore	48	1%	19	40%	29	60%
CHI Temple Street	24	1%	~	~	*	*
Bantry General Hospital	18	0%	6	33%	12	67%
CHI Crumlin	18	0%	~	~	*	*
Dun Laoghaire St Michael's	~	0%	0	0%	~	~
Ennis General Hospital	~	0%	0	0%	~	~
St Colmcille's Hospital, Loughlinstown	~	0%	0	0%	~	~
Total	4093	100%	1434	35%	2659	65%

~ Denotes five cases or fewer.

* Further suppression required to prevent disclosure of five cases or fewer.

TABLE A5.3: PATIENTS ADMITTED TO HOSPITAL FOLLOWING OUT-OF-HOSPITAL CARDIAC ARREST, BY LOCATION OF DEATH BY PATIENT SUBGROUP (2015–2019) – ARRIVED WITH ONGOING RESUSCITATION (n=2659), ARRIVED WITH RETURN OF SPONTANEOUS CIRCULATION (n=1434)

	Arrived with ongoing resuscitation (n=2659)		Arrived with ROSC (n=1434)	
	Ongoing	Ongoing resuscitation	ROSC (n)	ROSC (%)
ED	2290	86%	514	36%
ICU	~	~	98	7%
Other (Cath lab/ward/CCU)	*	*	23	2%
Incomplete data	337	13%	799	56%

~ Denotes five cases or fewer.

* Further suppression required to prevent disclosure of five cases or fewer.

APPENDIX 6: STAKEHOLDER SURVEY TOOL

The aim of this questionnaire is to explore the value and use of existing Irish data to drive improvement in identifying missed opportunities for organ donation.

The objectives are to:

- i Describe the perceived level of importance of existing data in driving improvement
- ii Make suggestions for additional data that would drive improvement
- iii Explore current use of data from the Irish National ICU Audit

Section 1: Demographics

1. Please tick one option that best describes your role:

- ☐ Organ Donation Nurse Manager
- ☐ ODTI (Administration)
- ☐ ODTI (National Organ Procurement Service)
- ☐ Clinical Lead in Organ Donation

Other – please specify

2. Prior to participating in the potential donor audit feasibility study, had you read any of the following national reports? (Y/N/Unsure)

	Yes	No	Unsure
Irish National ICU Audit 2018 report			
Irish National ICU Audit 2019 Preliminary report			
Out of Hospital Cardiac Arrest Audit			
Major Trauma Audit			

Section 2: Existing data

3. Please indicate the degree to which you feel the following data elements are important to drive quality improvement. Response options: Not Important, Slightly Important, Important, Very Important

OUTCOME DATA	Not Important	Slightly Important	Important	Very Important
ICU non-survivors				
Number of brain dead patients (as a percentage of all deaths) in ICU				
Conversion of brain dead patients to organ donors by unit				
Number of 'circulatory deaths' (as a percentage of all deaths) in ICU				
Conversion of 'circulatory deaths' to organ donors by unit				
Number of patients brought to ED following out-of-hospital cardiac arrest with ongoing resuscitation who died in hospital outside of the ICU (e.g. ED, CCU, Cath lab)				
Number of patients brought to ED following out-of-hospital cardiac arrest with ROSC who died in hospital outside of the ICU (e.g. ED, CCU, Cath lab)				
Number of patients who died with significant head trauma in the Emergency Department				
Number of patients who died in hospital with an ICD-10 code suggestive of a devastating brain injury				
PROCESS DATA	Not Important	Slightly Important	Important	Very Important
Family approached				
Family assented				
Patient donated				
Patients referred to organ donation personnel				
MISSED OPPORTUNITY DATA IN ICU (FOR BRAIN DEATH AND 'CIRCULATORY DEATHS')	Not Important	Slightly Important	Important	Very Important
Reasons why families of brain dead patients were not approached				
Reasons why patients not referred to ODP				
Reasons why brain dead patients did not become donors (i) why families were not approached, (ii) families assented but did not become donors, (iii) refused assent				

4. What other data elements may be important for driving improvement in identifying missed opportunities for organ donation? Please also give reasons for your answer.

Section 3: Current use of the Irish National ICU Audit

5. Do you access the Irish National ICU database for your base unit? (Never, Rarely, Sometimes, Often, Very often)	
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	Yes	No	N/A (ODTI Respondent)
6. Can you access the Irish National ICU database for other units within your Hospital Group?			

7. Please describe any barriers to using the Irish National ICU Audit to drive quality improvement in identifying missed opportunities for organ donation

	Yes	No
8. Have you attended any training for using the data from the Irish National ICU Audit?		

	Yes	No
9. Would you be interested in attending further training to access and interpret data from the Irish National ICU Audit?		

	Yes	No
10. Do you have any specific training needs from the Irish National ICU Audit?		
If yes. please specify		

APPENDIX 7: COST ESTIMATES FOR THE POTENTIAL DONOR AUDIT

Table A7.1 demonstrates the estimated costs for the audit development phase of a PDA within NOCA. Costs may vary slightly depending on the solutions. The costs for subsequent national implementation will be calculated during the audit development phase and will take account of solutions for data collection, processing and reporting.

TABLE A7.1: ESTIMATED COSTS FOR THE AUDIT DEVELOPMENT PHASE OF A PDA WITHIN NOCA

Cost items	Detail	Estimated costs (€ per annum)
Human Resources	Audit manager (1 FTE)	€90 000.00
	Data analyst (1/5 WTE): Support dataset development; lead data cleansing and validation; analyse findings; health service provider reports; overall findings report; feedback on dataset	€15 000.00
	Technical analyst (1/5 WTE): IT support and information governance	€19 000.00
Communications	Facilitate focus groups with patient groups	€10 000.00
	Lead public engagement on audit	
	Information leaflets	
	Audit pilot information pack for health service providers	
	Lead clinical engagement – conferences, meetings, etc.	
	Development of local reports – dashboard	
	Development of national report	
Total		€134 000.00

FTE: full-time equivalent

WTE: whole time equivalent

There are currently six ODNMs in post. The feasibility study identified that data collection for one ICU in each Hospital Group can readily be absorbed as part of their role for the development phase. Further audit implementation will be dependent on additional organ donation resources required. This will be considered and costs included in the proposal for further implementation.

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