Using Agent-Based Social Simulations to Inform Organ Donation Policymaking: Adopting the Spanish Approach in Sweden

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Abstract. Organ donation is a crucial aspect of healthcare, yet, the number of donors is insufficient to cover the demand for transplant procedures. In the European Union, around 15 people die each day waiting for a life-saving organ. National policies differ greatly among countries, but it is unclear how successful policies affect Deceased Organ Donation when introduced in other settings. This paper explores the use of Agent-Based Social Simulation (ABSS) to inform organ donation policymaking. It provides policy actors with a safe environment to investigate the consequences of different policy interventions without the risk of harming people. We present a simulation model of the Swedish organ donation system, where we can investigate the impact of Spain's policy approach, which has the highest DOD rates in Europe. The results highlight the potential of ABSS as a tool for evaluating policy interventions in complex healthcare systems, enabling policymakers to identify and evaluate strategies before implementation.

Keywords: Deceased Organ Donation · Public Health · Policy Support · Agent Based Social Simulation

1 Introduction

The global demand for organ transplants increases due to growing rates of diabetes, obesity, hepatic disease, and aging population. The World Health Organization (WHO) has emphasized the importance of striving for national self-sufficiency to fulfill transplantation needs since 2010 [21]. There is great diversity between, but also within, national public health systems regarding the implementation of Deceased Organ Donation (DOD) policies as well as in the resulting donation rates. With limited global policy guidance, comparative and exploratory policy analyses are vital means of increasing DOD rates.

In Europe, Spain is an outlier with historically high rates, reaching 49.4 donors per million population (pmp) in 2023 [18]. Still, the demand for transplants is increasing, with the number of kidneys transplanted reaching only 5.5% of the patients who began dialysis in Spain as of 2019 [16]. Sweden has recently reached 25 donors pmp, a rate attained by Spain in 1994 [11]. Measures such as implementing *donation after circulatory death* (DCD) or assumed consent have not yet led to substantial improvements. Yet, understanding and replicating the success factors from the Spanish system could increase donation rates in Sweden.

Agent-based Social Simulations (ABSS) emulate human behavior and systemic processes allowing us to explore *what-if* scenarios and to understand complex causal mechanisms within the referent system. ABSS can be particularly useful to support policy design, where real-world experiments to investigate the consequences of policy changes are ineffective, unfeasible, or unethical.

The goal of this paper is to demonstrate how ABSS can inform DOD policy-making. This is achieved through the generation of synthetic data, which provides policy actors with an innovative approach to navigate the complex DOD system. Particularly, we project the Spanish DOD policy approach on Sweden's landscape, which provides a framework for scenario development in relation to organ donation. The research questions we address in this paper include:

- How can social simulations be used to inform organ donation policy-making?
- How can trajectories of organ donors be modeled?
- How can relevant scenarios be developed and integrated into the model, based on other countries' organ donation policies?

The rest of the paper is organized as follows: Sec. II provides a background on organ donation and introduces Sweden's DOD system. Sec. III, presents the Spanish DOD policy approach, Sec. IV and V describe the conceptual and implemented model respectively, Sec. VI present initial results and Sec. VII discussion, limitations and future work.

2 Background

National organ donation and transplantation systems perform a critical role of transferring organs from donors to patients who need organ transplants. DOD systems exist at the intersection of medical ethics, individual choices, national regulations, and practical limitations. Not only are there strong regulative aspects and conflicts of interest, but organizational and economical barriers influence the work of clinicians, affecting the system's efficiency. Policy changes have been known to cause unintended consequences [3, 6].

In Sweden, DOD can happen after Brain Death (DBD) or Cardio-circulatory Death (DCD) and only people deceased in Intensive Care Units (ICUs) which match donation criteria are considered for the procedure. *Local donation clinicians* at the ICUs as well as regional or national *Transplant Coordinators* investigate medical viability criteria and consent before the removal of the organs (*donation*). The organs are then assigned to patients on the waiting list and transferred into recipients (*transplantation*).

The Swedish government tasked *Socialstyrelsen*, the National Board of Social Affairs and Health, with increasing DOD rates. Policy changes included restructuring patient consent as *opt-out* (assumed consent), removal of family veto, and the adoption of controlled DCD (cDCD), where cardiac arrest follows planned withdrawal of life-sustaining treatment. While the policy changes are similar to Spain's, they did not result in comparable outcomes as they fail to take in consideration the years of monitoring and tailored research informing Spanish policy changes.

This highlights the limitations of adopting policies as opposed to a broader policy approach. To be able to explore and better align the Swedish system with the Spanish policy approach, precision public health policies are required. ABSS provides the means to do so by centralizing the individuals (agents) and their characteristics, behaviors, and goals so that the consequences of policy interventions can be tested on virtual populations. Ethically, this mitigates risks associated with implementing policy with sub-optimal or harmful outcomes [20]. Mismanagement of organ donation could negatively affect trust in the system and lead to decreasing donation willingness [8]. Recent policy changes in Sweden have negatively affected the rate of people declaring their will to donate [1].

From a public health policy perspective, ABSS has proven its potential to explain causal mechanisms and complex system dynamics [19]. Within DOD, ABSS focused on exploring allocation policies [12, 15, 17] and multiple listing [7]. Additionally, we could demonstrate how suitable models can be generated from legal documents [2]. Models calibrated on historical empirical data are capable of 'capturing details of reality' and perform well in defined scenarios [12]. Further, ABSS allows for the continuous 'tweaking' of policies, one of the many benefits of the precision public health approach [14].

3 The Spanish Policy Approach: Lessons Learned

The Spanish policy approach acknowledges the high complexity of organ donation systems. Recent analyses of factors leading to Spain's success identifies dedicated institutions, quality assurance processes, detailed reimbursement schemes, and comprehensive training programs [16]. At the core of the Spanish approach is the National Transplant Organization (*La Organización Nacional de Trasplantes*, ONT), which created the Spanish Quality Assurance Program in the Deceased Donation process (QUAPDD). QUAPDD guided data collection, continuous internal monitoring and periodic external audits, metric discovery and data analysis (see Fig. 1). QUAPDD was not only able to estimate the size of the potential donor population but also to determine how and why potential donors do not become actual donors [4, 10].

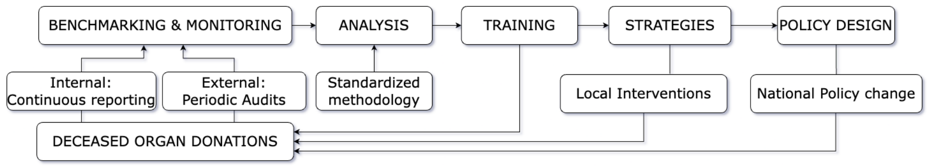

Fig. 1. Reductive schema of Spanish policy approach for DOD improvement.

3.1 Benchmarking and Monitoring

In Spain, from 2003 to 2007, Transplant Coordinators (TCs) reported data from 106 public ICUs to identify best performing hospitals at different phases of the donation process, including: 1) referral of possible donors to ICUs, 2) management of potential donors within the ICU (including evaluation of medical viability, and brain death diagnosis), and 3) obtaining consent. The analysis considered three indicators:

- Indicator I. Percentage of brain deaths in ICU compared to all brain death cases. Inclusion was determined via a list of ICD codes as primary or secondary diagnoses; the list accounted for 95% of national brain death etiology.
- Indicator II. Percentage of eligible donors pending consent to become actual donors. External audits revealed that certain hospitals were less efficient in routing eligible donors to donation.
- Indicator III. Analysis of consent to donation disproved the previous hypothesis that ethnicity and age impact consent rates [10].

3.2 Interventions

Six excellence hospitals were selected for further analysis [10]. The teams, protocols and practices at these hospitals were qualitatively studied, the results informed guidelines forwarded to all other hospitals. In Spain, as in Sweden, becoming an organ donor requires premortem ICU admission. A study revealed that nearly 40% of all possible donors were neither ventilated at death nor referred to a TC, as DOD was not considered [5]. Moreover, many brain dead patients were declared dead in hospital wards, not ICUs, excluding them from donation regardless of their will. An objective was to expand the potential donor pool by admitting patients to ICUs for non-therapeutic purposes through the practice of *Intensive Care for Organ Donation* (ICOD)[11]. While this does not affect the legal requirements for declaring death, it allows more patients matching donation criteria to become donors.

Monitoring previously exposed that 25% of brain dead patients were not considered medically viable for donation by TCs and local donation clinicians. To counteract this, the ONT established a medical team available at all times to provide counsel to ICU clinicians [11]. Even so, many eligible donors' condition fell outside the guidelines for medical viability. These guidelines were reassessed and changed, their impact monitored through the established pipeline. Interventions guided the evolution of national Spanish policy through the ONT.

3.3 Policy Design

Nationally, workplace safety regulations and medical advancements in neurological treatment were implemented. This led to a reduced pool of possible donors, as cerebrovascular disease and traffic accidents are the major suppliers of donors [4]. Yet, Spain increased its donor rate steadily [11]. At the time, Spanish law advised a donor age limit of 65-70 years. Given the observed prevalence of aging possible donors, the ONT proposed expanding age and risk criteria for DOD. Concerns around organ quality were addressed in longitudinal studies, among other things showing that patients under dialysis have a higher risk of death than those receiving a kidney from older donors [9, 13]. The ONT concluded that, although older donors provide less organs on average, there is no evidence that donor age impacts the quality of transplants. The approach also highlighted the need for cDCD protocols, which Spain allowed in 2012 following ONT's recommendation. A common concern was ICU bed capacity, which was however unaffected. In 2016, DCD contributed to 10% of the overall deceased donation rates and its impact is increasing, reaching 50% in 2023 [11].

4 A Model of the Spanish Policy Approach in Sweden

The model development consists of two steps: First, we implement a baseline model of the current Swedish organ donation system. This is to replicate its dynamics and to serve as comparison for assessing the effects of policy changes. Second, we develop scenarios of potential policy modification where we follow the Spanish policy approach's main phases. These scenarios are then applied to the Swedish model to investigate consequences.

4.1 The Swedish Baseline

Sweden is known for transparency and wealth of digitalised publicly available data. Socialstyrelsen provides data on all deaths occurring in the country according to the international *ICD-10*[5] standard. The Swedish Emergency Care Registry (*Svenska Intensivvårdsregistret*, SIR), provides data on most common causes of death for actual donors, donor discovery rates, and contact to Transplant Coordinators.

The Baseline sets all variables to the state of year 2023, i.e., 10.5 million population, a brain death rate of 0.49 pmp, 33 Local Donation Clinicians (Staff). A TC is contacted in 64% of cases, 62% of TC contacts lead to donation. The number of ICUs is kept at 81.

4.2 Scenario Development

Projecting the Spanish policy approach onto the Swedish landscape required an assessment of comparability. Spain (around 49 million inhabitants) has a

[5] International Statistical Classification of Diseases and Related Health Problem: https://icd.who.int/browse10/2019/en

higher population and physician density than Sweden. Yet, the public health systems, population health, and socio-legal systems provide a suitable foundation for comparison (see Tab. 1)[6].

Table 1. Comparison of Spanish and Swedish healthcare systems

Metric	**Spain**	**Sweden**
Deceased Donor Rate (pmp)	57	25
CT scanners, MRI units and PET scanners (pmp)	44	43
Deaths in hospitals	50%	36%
Population coverage for a core set of services	100%	100%
Health expenditure per capita (USD PPP)	4 432	6 438

Benchmarking and Monitoring We determine the best performing hospitals with respect to the first two indicators. The third indicator was inconclusive for Spain; which does not exclude the possibility that demographic factors influence consent rates in the Swedish context. We add the rate of contacts to TC for identified *Potential Donors*. Consent checking involves a first inspection of the registry and, if the donor was not registered, contacting the families or documenting that there were unsuccessful attempts at contacting relatives.

Interventions The potential impact of ICOD on donor rates is modeled by estimating the donor pool for all brain death cases in the country matching ICD-10 codes leading to donation. TC contacts and the rate of *Possible Donors* progressing to *Eligible Donors* are analyzed for the best performers. Note that Sweden already has a 24/7 TC coverage.

Policy design As there is no age restriction to donate in Sweden, modeling the policy change for age expansion is unnecessary. The modeling of how cDCD influences DOD is outside the scope of this project. We define the simulated scenarios and interventions as shown in Tab. 2.

4.3 Conceptual Model

The main agent types in the model are *Donors*, *Local Donation Clinicians*, and *TCs*. The donor agent can transition through four states:*Possible* (patient with acute neural injury, recovery possible), *Potential* (patient approaching Brain Death, recovery impossible), *Eligible* (a potential donor for whom the TC was contacted, death is declared), and *Actual* (a medically viable deceased patient upon whom an incision has been made with the purpose to retrieve organ(s) for transplantation, consent from patient or relatives has been investigated) (see Fig. 2). Local Donation Clinicians are randomly created in ICUs according to SIR data.

[6] Data from 2023 or closest available year. Source: OECD

Table 2. Scenarios based on success factors from the Spanish organ donation system.

Scenario	**Description**
1. Baseline	Replicates Sweden's 2023 policy. Used for comparison of the results from the other scenarios.
2a. Increased TC contact rates	The value for TC contact rates is increased to the average of best performing Swedish hospital (contact_TC = 87.5%).
2b. Increased Local Donation Clinicians	The coverage of local donation clinicians is maximized (all ICUs have specialised clinicians (staff) available).
2c. Increased consent and viability rate	Medical viability and obtaining consent is set to the average of best Swedish hospitals (consent_and_viability = 82%).
2d. Best Practices	Combination of scenarios 2a, 2b, and 2c.
3. ICOD	Increase of brain death rate, which implies access to possible donors in both ICUs and hospital wards.
4. Best Practices + ICOD	All interventions adopted, inputs set at local best values.

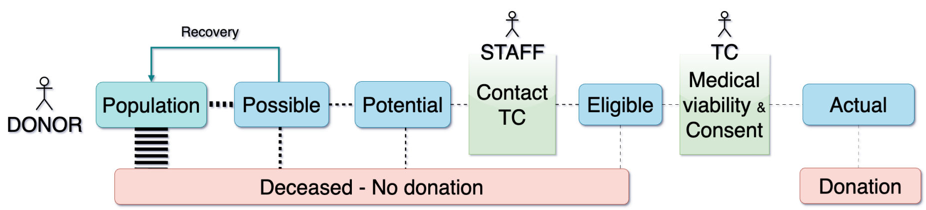

Fig. 2. Conceptual model of the donor state trajectory.

Once patients matching brain death criteria are in ICUs (Possible Donor), they are assigned specialized clinicians (staff). Data from SIR indicate that 100% of potential donors are discovered, hence the lack of transition barriers from *Possible* to *Potential*. If the patient is not connected to a Staff agent, they are declared dead (*no-donation*). If Staff is assigned to the Possible Donor, they proceed to the state of Potential Donor. The Staff agent will contact a TC for the Potential Donor case (depending on probability *contact_TC*); the TC returns the result of their assessment of *Medical Viability and Consent*. Only if both assessments are cleared, can the donor undergo the transition state to Actual Donor.

5 Implemented Model

The model was implemented in Netlogo version 6.4.0 and is accessible via GitHub[7]. Please consider that this project is a work in progress and new versions of the

[7] https://github.com/cybertilla/SimODSweden

model will be published. A screenshot of the model's user interface can be found on GitHub and is not shown in the paper due to the page limit.

5.1 Agents and Scheduling

The physical arrangement of the model's patches is based on the map of Sweden. Three variables are assigned to patches: land, ICU and staffed. The *n-icus* slider determines how many of the patches with land value 1 become ICUs. The *Staff* slider determines how many ICUs have Staffed value of 1, meaning they house clinicians trained in DOD. The generation of patients follows a Poisson distribution calibrated on the averages obtained from empirical data. The model is designed to represent each day as one tick. Of influence are the initial settings in terms of Population, Infrastructure and the Intervention sliders.

5.2 Parametrization

The parameters of the model are shown in Tab. 3 and represent the values needed to implement the scenarios and policy interventions defined in Tab. 2.

Table 3. Parameters of the simulation model.

Parameter	**Description**	**Determines State Transition**	**Local Optimal Value**	**Baseline Scenario**
total_population	Population size of country	Possible	10.54M	10.54M
bd_rate	Brain death rate	Potential	0.89	0.49
contact_TC	Contact rate TC	Eligible	87.5%	64%
consent_and_viability	Medical eligibility and consent	Actual	82%	62.17%
Staff (specialised)	Number of ICUs with Specialised Staff	Staff	#ICUs	33
#ICUs	Number of ICUs	Staff	100	81

Brain Death rate and ICOD Indicator I from the Spanish benchmarking study has been approximated for Sweden via a list of ICD-10 codes representing the majority of DBD for the retrospective cohort 2015-2023. This entailed mapping the national codes to the international standard ICD-10. Included codes account for 99% of DBD through the years. On average 3453 people died each year who matched criteria for Possible Donors, of these deaths, 1915 occur in ICUs. For the past 9 years, brain death occurred in ICUs in 55.46% of cases. The Swedish donor pool can be expanded to consider the remaining 44.54% of deaths matching criteria for DBD through the practice of ICOD.

TC contact Indicator II was approximated with the rates of contacts to TC, reported by SIR. On average, 64% of Potential Donors in ICUs are referred to TC (Baseline scenario). The averaged rate of best performing hospitals is 87.50%. TCs are assumed to be available at all times and capable of handling any amount of requests simultaneously.

Consent and Medical Viability On average, 62.17% of TC contacts lead to donation (Baseline scenario) and the best performing Swedish hospotals achieved rates of 82%. The percentage of people not consenting to organ donation is included in the transition rate from Eligible Donor to Actual Donor.

6 Results

Each simulation runs for 1 year and is repeated 26 times (9490 ticks), the first year is considered warm-up and excluded from analysis. Results are reported for the following metrics: Actual Donor rate (pmp) and Donor State, meaning the number of Possible, Potentials and Eligible and Actual Donors). Fig. 3 shows average number of Actual Donors(pmp) per year for each scenario. Baseline, or Scenario 1, is the reproduction of empirical values via the simulation, which provides partial verification and sanity check of the model. The actual donor pmp for Scenario 1 is 23.87 and as the model considers the variation contained in the retrospective cohort 2015-2023, the average pmp is slightly lower than the latest empirical pmp (2023); Baseline outputs a sufficient estimation of Actual Donor pmp with respect to historical trends. Scenario 2a (optimal TC contact) and 2c (optimal consent and viability) result in a slight increase in annual pmp, around 29 Actual Donors pmp. The effect of increasing the local donation clinicians (Scenario 2b) is more pronounced, 64 pmp. ICOD's effect (Scenario 3) increases the donor rate more compared to 2a and 2c, yet, does not surpass 2b. The forecast of annual pmp after implementing all Interventions and supporting them with increased numbers of local donation clinicians (Scenario 4) outperforms all other scenarios, reaching 228 pmp.

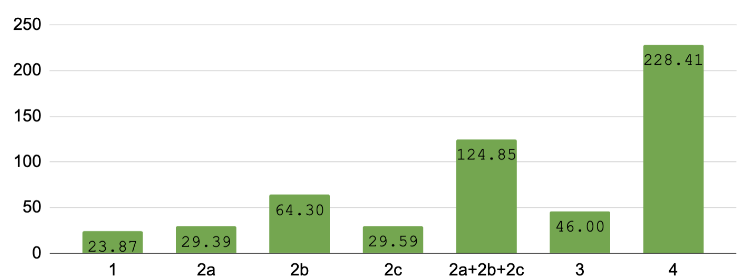

Fig. 3. Average number of actual donors (pmp) per year for the different scenarios.

Fig. 4 shows the state progression of the donors during the simulation. As an example, in Scenario 1, the baseline scenario, 24 452 possible donors were simulated, 14 568 remained in the Possible Donor stage (e.g. due lack of local donation clinicians), 1 767 dropped out in the Potential Donor stage (e.g., as no contact with the TC was initiated), 4 935 eligible donors dropped out due to TC exclusion of consent or medical viability, ultimately leading to 3 273 Actual Donors.

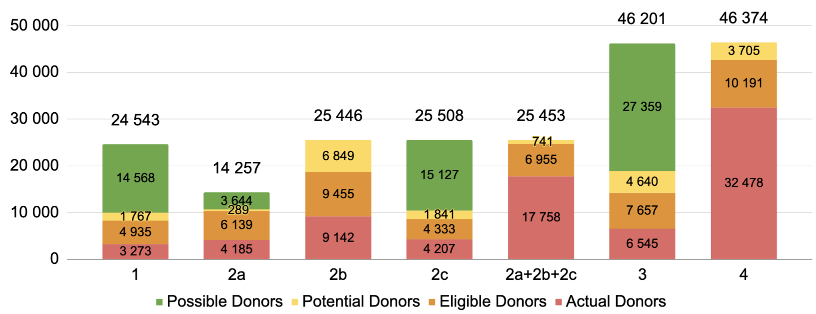

Fig. 4. State progression of donors, absolute values per year and scenario. The numbers on top of the bars represent the total number of possible donors, i.e. deceased with suitable ICD-10 code. The numbers in the bars represent the furthest state progression in the simulations.

The proportion of donors at different states gives insight into the forecast functioning of the DOD system in different scenarios. Of note is the absence of Possible Donors in Scenarios 2b, 2a+2b+2c and 4, indicating that all patients matching criteria were progressed to other states thanks to the increase of local donation clinicians. Consider the differences between Scenario 3 and 4: of 46 201 patients considered for donation in Scenario 3, 14% (6 545) became actual donors, while 70% of patients proceeded to Donation in Scenario 4, despite the total amount of patients being similar. This shows that implementing Interventions is most effective if combined with staff expansion; especially in consideration of costs inherent to progressing patients through donor states.

7 Discussion and Future Work

The goal of this paper was to demonstrate the potential of ABSS to evaluate policy interventions for DOD in Sweden by modeling key aspects of Spain's successful approach. The simulation results show how increasing the number of Local Donation Clinicians, optimizing TC contact rates, and implementing ICOD could potentially increase Sweden's donor rates. However, the model also highlights that isolated policy changes may have limited impact unless they are embedded within a broader national strategy.

With this project, we want to support and stimulate healthcare policy discussions, given the increasing demand for organ donations and the need for innovative solutions. Sweden's current system faces challenges in meeting transplant needs, and leveraging insights from other donation systems (for instance the Spanish) could provide a viable strategy for improving donor rates. ABSS has the great potential to enable policy actors to analyze and assess the potential effects and impact of policy changes prior to their implementation and in changing societies. It further provides policy actors with a valuable tool to better understand the consequences of policies under different circumstances.

This project is still ongoing and the results we present in this paper are work in progress. As a next step, we intend to investigate a variety of long-term temporal dynamics of organ donation policies, including how socio-demographic changes (e.g., aging populations, urbanization, and lifestyle shifts), might affect the outcomes and success of organ donations in Sweden.

All data used in this paper was sourced from publicly accessible databases; SIR and Socialstyrelsen provide anonymised data as part of their public service.

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