Evaluating Deceased Organ Donation: A Programme Theory Approach

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Summary

• Why a programme theory approach?

• How?

1. Elucidating the complexity of the problem/programme: Logic map

2. Contrasting complexities 1) with single-lever theories proposed in 2 typical OD programmes (presumed consent & nudges)

3. Reflecting on how this approach will help with the evaluation design
Organ Donation: Facts and Figures

Kidneys are in the highest demand

- 81% of all patients waiting are in need of a kidney.
- 14% of patients are in need of a liver transplant.

In 2011, 2 patients were added to a kidney waiting list in Europe every hour. That's 68,073 new patients!

23,485 patients received a kidney.

12 patients died every day due to lack of organs.

Organ shortages remain the main obstacle in transplantation medicine!

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• For two decades, Spain has maintained the highest deceased donor rate in the world and institutions (WHO, EU) promote the wider application of the so-called ‘Spanish Model’

• In 2010, a European Union directive aimed at achieving uniform quality and safety standards and improving waiting times for transplants gave to Spain the role of improving the training of transplants coordinators.

• The same year, the World Health Organization recommended to reproduce the Spanish model of organ donation worldwide assuming that self sufficiency in the supply of organs will follow and the universal trend of organ trade and trafficking will therefore be eliminated
DOING THE LOGIC MAP
Doing the Logic Map

- Comparison UK/SPAIN-WUN-funded project
- Development work for a larger bid
- 2 stakeholder events (one in Barcelona and one in Leeds) + 2 public involvement events
- Rapid realist review of the literature.
## Family Refusals Latest Data (2012)

<table>
<thead>
<tr>
<th>Country</th>
<th>Population</th>
<th>Deceased Organ Donors</th>
<th>Multi-organ</th>
<th>Number of interviews requesting consent</th>
<th>Family Refusals</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spain</td>
<td>46.8 million</td>
<td>35.1 (pmp) 1643 (total)</td>
<td>27.1 (pmp) 1,267 (total)</td>
<td>1948</td>
<td>305 refusals (15.6%)</td>
</tr>
<tr>
<td>UK</td>
<td>62.8 million</td>
<td>18.5 (pmp) 1164 (total)</td>
<td>13.0 (pmp) 816 (total)</td>
<td>2906</td>
<td>1236 refusals (42.5%)</td>
</tr>
</tbody>
</table>

Council of Europe, 2013
Are families to blame for refusals?

Reasons frequently given in SPAIN

For refusal:
- Refusal during life time
- Problems with health system
- Maintaining the body intact
- Religious beliefs
- Family distress
- Flat refusal

For donation:
- Acceptance after information
- Living will
- Grateful to health system
- Solidarity
- Reciprocity

Individual altruism is frequently used as the argument to explain this phenomenon

Reasons frequently given in the UK

For refusal:
- Fear of mutilation
- Lack of trust in medical/nursing staff
- Poor communication regarding patient
- Not knowing patients wishes
- Not understanding futility decision or brain stem death
- Culture/religious grounds
- Timing
- Believing the patient has been through enough
- Wanting the patient to stay whole
- Divided over the decision
Would you donate your organs after you die?

Europeans and organ donation

Fieldwork: October - November 2006
Publication: May 2007

Report

Country Results

<table>
<thead>
<tr>
<th>Country</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>SE</td>
<td>81%</td>
</tr>
<tr>
<td>MT</td>
<td>75%</td>
</tr>
<tr>
<td>FI</td>
<td>73%</td>
</tr>
<tr>
<td>BE</td>
<td>71%</td>
</tr>
<tr>
<td>DK</td>
<td>69%</td>
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<td>NL</td>
<td>69%</td>
</tr>
<tr>
<td>FR</td>
<td>67%</td>
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<tr>
<td>IE</td>
<td>67%</td>
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<tr>
<td>PT</td>
<td>66%</td>
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<tr>
<td>UK</td>
<td>63%</td>
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<tr>
<td>SI</td>
<td>63%</td>
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<tr>
<td>LU</td>
<td>62%</td>
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<tr>
<td>EE</td>
<td>58%</td>
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<td>ES</td>
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<td>EU25</td>
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<tr>
<td>EL</td>
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<tr>
<td>AT</td>
<td>33%</td>
</tr>
<tr>
<td>LV</td>
<td>29%</td>
</tr>
</tbody>
</table>
This process has an iterative, recursive structure involving the coordination of a multiplicity of stakeholders with different and sometimes competing interests.
Organ transfer necessitates that body parts be removed from donors who appear to be alive, sustained by a complex array of technologies.

**Step 1 of the logic map: Definitions of “death” are contested and contextual**. Brain death and cardiac death are legal in the UK. Cardiac death is illegal in Germany. Organ donation for transplantation requires the coordinated effort of hundreds of players (patients, donors, recipients, families, nurses, physicians and surgical teams from assorted departments and institutions).

DODT is a complex medical procedure dependent on time-pressured coordination of multiple skills and services;

**BUT DODT is equally a social process depending on altruism**. THESE PROCESSES DO NOT OPERATE IN PARALEL. THEY INTERACT IN COMPLEX WAYS
To understand those processes and interactions we need to draw on conceptual schemas extracted from clinical, management, social science and public health theories (Steiner and Jacobs, 2008). Titmuss already demonstrated how ‘altruism’ is socially constructed (The Gift Relationship).

DODT is a prime example of a complex adaptive system in health care (Plsek and Greenhalgh, 2001), operating with multiple, self-adjusting, unpredictable and interacting pathways.

In the UK 2011: Two public policies addressed at DODT:

- Nudges for organ donation (Behavioural approach to driving licence registration)
- Presume consent policy in Wales
• Countries with high donation rates apparently share a common denominator: presumed consent legislation where all deceased are potential donors in absence of explicit opposition before death. Opt-in/Opt-out

• The **heated debate** ‘presumed consent versus informed consent’ has some powerful supporters behind each team

• This debate extends to the research literature with studies offering contradictory data to whether presumed consent countries produce significantly higher organ donation rates (Johnson and Goldstein 2003, 2004; Abadie & Gay 2005).
The Process of Informed and Presumed Consent

Donor identified

Consult official register of wishes (ODR)

Registered Donor

Consent to Donate

Refusal to Donate

Non Registered Donor

Consent to Donate

Refusal to Donate

In both situations the next of kin is asked to consent to organ donation on behalf of the individual.
Driving licence online applicants have to tick one of three options below to answer a question on organ donation before they can complete their application:

- Yes, I would like to register
- I do not wish to answer this question now; or
- I am already registered on the NHS Organ Donor Register

Non-regulatory interventions designed to influence behaviour by modifying the context in which people make choices (also called ‘choice architecture’ interventions or nudges Thaler and Sunstein (2009).

Choice architecture policies are widely contested both on theoretical grounds (Sugden, 2009) and in respect of their empirical basis (Science & Technology Selected Committee, 2010)

The role of emotions and affective attitudes attached to organ donation (Manzano, 2014)

- Family decision makers bear the emotional impact of death
- Possible registrees deal with the so-called ‘ick factor’ (feeling disgust towards the idea of organ donation) and ‘the jinx factor’ (the superstitious belief that registration could lead to harm or death for the registrant), these being two of the most prominent instinctive reactions to registration (Morgan et al, 2008).
- How the ick and jinx factors are taken into account when attaching registration to ‘dangerous’ activities (i.e. Driving)
Both policies are single lever theories directed only at Step 4
Reasons for refusal UK

Fear of mutilation
Lack of trust in medical/nursing staff
Poor communication regarding patient
Not knowing patients wishes
Not understanding futility decision or brain stem death

Culture/religious grounds
Timing
Believing the patient has been through enough
Wanting the patient to stay whole
Divided over the decision

Both policies are single lever theories directed only at Step 4
HOW TO EVALUATE COMPLEX SYSTEMS
1. Modelling micro-processes

The programme theory approach allows inspection of the implementation process to drill down from macro to meso to micro levels (Funnell and Rogers, 2011).

Logic map allows inspection of the integrity of the entire implementation chain and permits the identification of the strategic flows and blockages.

Narrow focus to any step in the chain and use a logic model to explore the delivery of component process. As an example the family interview.
2. Comparative Case Studies

• ‘Comparative process tracing’ has evolved in the comparative and historical social sciences (George and Bennett, 2005)

• The idea to construct explanations of why conversion from, say, point D to E differs between the systems and, in so doing, to ascertain transferable lessons on system improvement.

• Example: Donor identification is facilitated by the co-presence of a range of structures, procedure, and historical practices.
CONCLUSION

BEWARE OF ONE-SIZE-FITS-ALL SOLUTIONS