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Ethical Un/Certainties in the Face of Deemed Consent for Organ Donation in the UK

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Deceased Organ Donation: Problem-Solution Story

A ‘problem-solution’ narrative exists around deceased organ donation.

The problems:

1. The number of patients needing a transplant rising (Prabhu, 2019; Noyes et al., 2019).
2. Few people are signing up to the register (Prabhu, 2019; Bea, 2021).
3. Refusal rates for organ retrieval by relatives is high (Prabhu, 2019; Shaw, 2017; Bea, 2021).

Organ donation as a moral good (Prabhu, 2019); cost effective (Noyes et al., 2019); improves lives (Noyes et al., 2019); supported by the public (Prabhu, 2019).

The ‘Solution’: Increasing Organ Donors

- People will be deemed to have agreed to donating their organs after their death unless they register their decision to opt-out on the NHS organ donation register.
- Deemed consent for deceased organ donation was first introduced in Wales in 2015, then England (May 2020), and more recently Scotland (March 2021).
- A ‘soft’ opt-out is considered to exist in practice. Families are expected to support the donation decision made by their relative in life, although they can override this decision. The family veto, as it is known, has no legal basis (Noyes et al., 2019).
- In June 2021, NHS Blood and Transplant launched a new strategy, whereby deemed consent is considered vital in order to meet the strategic objectives by 2030.

Deemed Consent System: ‘Protecting’ the Public

- A number of ‘protections’ incorporated into the system:
  - the ‘opt out’ option (Prabhu, 2019)
    - an individual opposed to organ donation is more likely to opt-out under a system of presumed consent than someone who desires to donate is to opt in under an explicit consent system e.g. 5-6% of eligible population in Wales opted out in first three years of policy in force (Prabhu, 2019; Rieu, 2010; Noyes et al., 2019)
  - the family input
    - donor not formally registered, but told relatives (Rieu, 2010). Fewer families will override the deceased’s wishes in an opt out system and therefore enhance a deceased person’s autonomy (Rieu, 2010)

Deemed Consent: A Complicated Picture

- Familiar problems, different name?
  - Critique of an opt out system similar to that put towards an opt in system:
    - Registering intentions as (lacking) evidence (Shaw, 2017; Prabhu, 2019)
    - Difficulty overriding family overrule (Shaw, 2017; Noyes et al., 2019)
    - How informed the consent is provided for donation practices (Shaw, 2017; Prabhu, 2019)
    - Organs donated no longer gifted (Prabhu, 2019)
    - Majority of recipients wish to be certain that the organs were only retrieved in accordance with the donor's wishes (Bramhall, 2011)
    - A presumption is made in both systems and autonomous will violated either way (Cohen, 1992)
    - Can lead to tensions between HCPs and families (Bea, 2021)

Deemed Consent: A Complicated Picture

- (Limited) Support?
  - There has been high profile support for deemed consent in the past including Prime Ministers, patient groups, the British Medical Association Ethics Department, and the Chief Medical Officer (Rieu, 2010; Noyes et al., 2019).
  - There has been resistance to the deemed consent policy and a desire to focus on educating public and raising awareness so families decline less frequently (Fabre, 2014; Organ Donation Taskforce, 2008).
  - There have been calls to shift away from focusing on consent and instead move to reframing donation as an end of life choice, and a need to acknowledge the legitimate role of families in decision-making (Bea, 2021).

Deemed Consent: A Complicated Picture

- (Limited) Success?
  - Opt out countries have some of the highest and lowest organ donation rates (Willis & Quigley, 2014)
    - Perhaps because families objecting to deemed consent in principle (Shaw, 2017); an anti-donation backlash (Bea, 2021); policy is perceived as authoritarian and shifting control from individuals to the state (Lauri, 2009)
    - Intention or willingness does not translate into practice (Willis & Quigley, 2014)
  - Countries without opt out legislation have seen increasing donation rates after implementing changes in infrastructure (Willis & Quigley, 2014)

Ethical Uncertainty in Organ Donation

"One of the biggest obstacles to successful organ donation is uncertainty. It needs to be known what people want to do or not to do" (Farsides, 2012).

- Can consent be 'deemed'?
    - Reflected in the language and terminology around the policy e.g. 'presumed' / 'deemed'/ 'absence of objection' (Kious, 2015)
    - Silence equating to tacit consent (MacKay, 2015); indifferent to donation become donors by default (Modra & Hilton, 2015)
    - Challenging our common understandings of consent i.e. an active process, given explicitly (Veatch & Pitt, 1995; Saunders, 2012)

Ethical Uncertainty in Organ Donation

"Society needs to ensure that people feel safe to record their objections and that they would take the trouble to do so otherwise the system would do little to ease the conflict and uncertainty for the healthcare professionals" (Farsides, 2012).

- Do people have the ability to opt out?
  - Language barriers, cognitive impairment, technological access, knowledge of policy (Modra & Hilton, 2015; Bea, 2021)

Questioning the Ethics of Deemed Consent

- How informed are donors? Does this matter?
  - Does someone sign up for whatever donation entails or can they refuse parts of the treatment necessary to enable the donation to go ahead? (Farsides, 2012).
  - An autonomous person is not required to inform themselves more fully than they desire…need to be adequately informed, have time to deliberate, and not be coerced, but donation is about values and doing something acceptable (Farsides, 2012).
  - Staff need to be assured that what happens during donation is something that people hypothetically would have consented to had they chosen to become fully informed of the details (Farsides, 2012).
  - Potential donors can trust that what they are agreeing to is reasonable and proportionate to achieving their goal (Farsides, 2012).

Questioning the Ethics of Deemed Consent

- Who owns my body? Who decides what happens to my body?
  - Families?
    - Ignoring dissent from families may undermine trust in organ donation process and medical profession as a whole (Modra & Hilton, 2015)
    - Comparisons drawn with other forms of donation i.e. whole body donation where the family veto is excluded (Cay, 2019; Winkleman, 2016)
  - State?
    - Comparisons drawn with other procedures relating to bodies i.e. the retention of tissue during a Coroner’s post mortem whereby consent is not required as it may be required to establish cause of death (HTA, 2010)
  - Individual?
    - Opt out has made it their responsibility for what they want to happen to their body in their death (Farsides, 2012)

Questioning the Ethics of Deemed Consent

- Debates pitch the needs of the living vs the needs of the dead (Prabhu, 2019; Rieu, 2010)
  - Presumed consent relieve doctors' burden of having to ask grieving families for permission (Buggins, 2008)
  - Avoids additional strain on relatives in an excruciating situation (Prabhu, 2019; Spital & Taylor, 2007; Modra & Hilton, 2015)
    - Is it possible to reduce their emotions or the experience at the stage of the request? (Sque et al., 2008; Lock & Crowley-Makota, 2008)
  - Rights of the dead to non-interference, self determination and autonomy (Kluge, 2000; Veatch & Pitt, 1995; Rieu, 2010)

Ethical Uncertainty and Morality, Values, and Principles

- When considering uncertainty in body donation, researchers are encouraged to consider why healthcare professionals are drawing attention to the uncertainty? What is happening? What is being achieved? And what is at risk? (Machin et al., 2020).
- Are healthcare professionals questioning what is morally acceptable? And what constitutes ‘ethical’ practice in organ donation?
- Walker (1998) claims that morality is something we do to account to each other for our identities, our relationships, and the values that define our responsibilities. *“It is a way of expressing who we are, of understanding others, and holding others and ourselves to moral account”* (Verkerk et al., 2004).
- As researchers, can we glean healthcare professionals’ values and principles relating to deceased organ donation by focusing on the ethical uncertainties identified by healthcare professionals?

Today

- Given the recent introduction of deemed consent to England and Scotland, and the new strategy document for organ donation from NHSBT, it is timely to reflect on healthcare professionals' perspectives on the deemed consent policy, in particular the opt out and the family veto aspects of the process.

- Present emerging findings
  - Based on 24 in-depth, semi-structured interviews
  - Conducted in 2013 at a time when Wales had agreed to move to deemed consent, which would be introduced in 2015. The ideas were being pushed and mooted for England during the time of the interviews.
  - With clinicians and nurses across three wards (intensive care, theatre, and emergency) in one NHS Trust in the North West of England.

Today

- Initial thematic coding of the interview transcripts (Braun & Clarke, 2006)
  - Identify the areas of un/certainty for healthcare professionals when discussing deemed consent for deceased organ donation
  - How are these un/certainties created and portrayed by healthcare professionals?
  - How do healthcare professionals portray themselves and others when discussing the un/certainties surrounding the deemed consent system?
  - Why might healthcare professionals create un/certainty surrounding the deemed consent system, and what do they gain and lose by doing so?
  - What can we learn about healthcare professionals' principles and values relating to deceased organ donation?
- Research Ethics Committee and Research and Development approved
- Initial observations: a 'donation ethics' emerging?

A Loss of Consent

- *"…if it was a case of they're a potential donor, we are taking their organs no matter what you say, this is national policy, that would be a disaster. I think you would lose public faith and public involvement very, very quickly. You could just see the headlines, "Doctors stole my husband's organs". That would be disastrous." (A1-2 ICU Consultant Anaesthetist)*
- *"I think just a blanket saying we're going to take everybody's organs unless you do something about it I think is quite a dangerous precedent to set and a slippery slope to go down. Because, you know, where do you draw the line?" (AB1 – 3 Anaesthetic Consultant)*

Promoting Choice

- *"How you enable people to opt-out I think would be difficult. Because you are depending on, if it became much more proactive from the point of view of – I'm going to use slightly distasteful terms here – gathering organs, you'd have to be very careful as to how stringently you ensured that everybody did have a proper option to opt-out. If it was more along the lines of this is our way of having a discussion about it. But if we were to go these are our organs to do with what we want you'd have to have a very, very strong opt-out network there to be able to enable people who wanted to opt-out could opt-out." (A1-2 ICU Consultant Anaesthetist)*
- *"You've got elderly people who don't use the internet or are not aware of the opt-out version and you don't want them coming into hospital and then being harvested and it was something that they really, really didn't want. And also you've got to have some sort of failsafe than it just happening anyway and, oh, I didn't realise they'd opted out. It's one of them isn't it. It's a good idea in principle but whether we could pull it off and it be ethically correct and subject to the rules being bent a little." (B2 – 1 Theatre Staff Nurse)*

Genuine Consent?

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- *"I think if you felt strongly enough then you would opt-out. I think there would have to be really clear processes in making it very easy for people to be able to do that so it wouldn't be something that somebody felt they couldn't or wouldn't be able to do". (A4 – 2 ICU Ward Manager)*
- *"In terms of consent, I think it would be difficult to know whether patients have genuinely consented for organ donation with an opt-out system." (AB1 – 1 Anaesthesia/ICU Consultant)*
- *"But then would there be people who if they don't opt-out but you know that they really wouldn't want it, it's very difficult. You could have had these conversations but they've just physically don't…They might not know how to do it. It's very tricky…There isn't any sort of clear cut way that you'd guarantee to get everybody and to know what everybody's true wishes were." (A2 – 1 ICU Sister)*

Health Engagement

- *"I've got some misgivings about that really. I think the general engagement of people with major health service decisions or decisions affecting their wellbeing is fairly low and I think to expect people to opt-out is never really going to hit home to those people who haven't got time to think about it. I think a lot of people have got a kind of it's not going to happen to me attitude and I'll get round to that one day and never do. I think organ donation, you're always going to have demand outstripping supply and I think there are other ways of going about it really." (AB1 – 3 Anaesthetic Consultant)*
- *"…none of us think we're going to die tomorrow…So what you would end up with is potentially tricky situations for us in ITU in saying, well, there's no opt-out so we're going to take the organs…" (AE1 – 1 Consultant in Intensive Care Medicine)*
- *"And at what stage do you make the opt-out age? 16, 18? How many 18 year olds actually ever think about their own mortality? I certainly didn't when I was that age." (A1-2 ICU Consultant Anaesthetist)*

Informed Consent?

- *"I personally quite like the opt-out system…I think it will let you increase the number of possible donations that you've got. As long as the people understand." (A1 – 1 ICU Consultant Anaesthetist)*
- *"I wouldn't have any ethical qualms at all about it becoming an opt-out system as long as people knew what they were buying into." (AB1 – 2 Anaesthesia Consultant)*
- *"I hope it just raises awareness and people can go away and make a bit more of an informed choice themselves…If everybody has got a nice awareness they can make a nice informed choice of whether it's something they actually want to do or not." (B2 – 1 Theatre Staff Nurse)*
- *"I don't think it is right to withhold the information. Because what happens is when you're in that situation and then your relative is being kept alive you're very much within your rights to say why didn't anybody tell me this is what it was going to be like? It just adds stress and hurt to what is already a horrible situation I'm sure. But I think you probably should tell them but I think it might be at the cost of some organs." (B4 – 2 Theatre Operational Manager)*

Deemed Consent: Justified?

- *"I think there would still be the same problem that even if we presumed that everyone was for donation would that change the relatives? Would we still ask the relatives? And if we would how does that make it any different from the opt-in system?" (A2-3 ICU Sister)*
- *"I think it would depend on what exactly opt-out was…I think if there was still room for consultation with family and taking into consideration families' wishes then it wouldn't actually be that different from the situation we're in currently." (A1-2 ICU Consultant Anaesthetist)*
- *"So is it going to solve anything? …even if I don't opt-out and you come to the relatives and say he's not opted out so we're having these organs and they say no, no are you going to do that? You're not going to do that are you." (A2 – 2 ICU Charge Nurse)*

Who is Family?

- *"I think it would be extremely difficult for us to ever sanction taking someone's organs without the family agreeing. Because the family are the only people that are still alive and left behind…The problem is who do you ask and how many people get involved in the decision? How do you decide whose opinions are important?...There may be all sorts of people come forward and everybody always feels they have an equal right to the information and have an equal right to give their opinion…What do you do in that circumstance? It's not easy and it can cause conflict." (AB1 – 4 Consultant in Anaesthetics and Intensive Care)*

Whose Wishes?

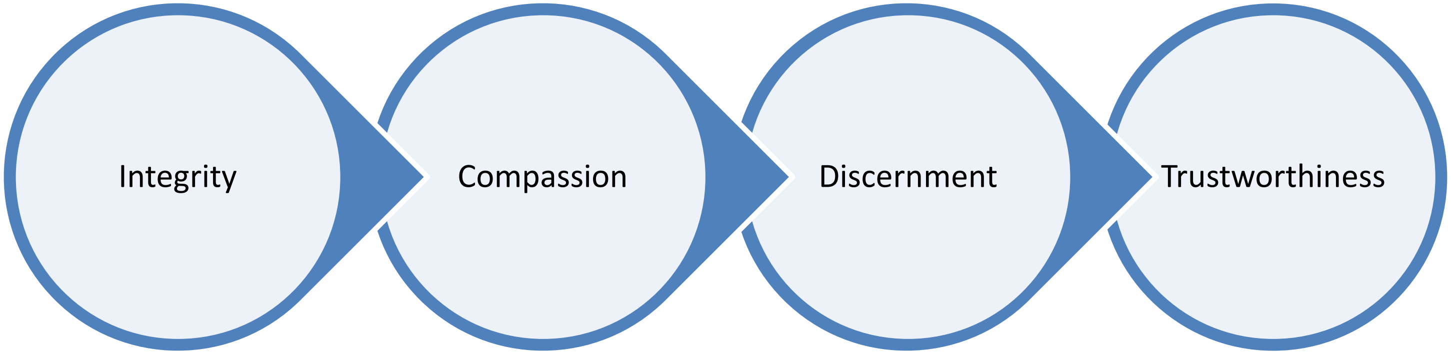
- *"Opt-out, the problem is that when the family disagree you don't know if was just their wishes or the patient's wishes then." (AB1 – 4 Consultant in Anaesthetics and Intensive Care)*
- *"Personally, I think they (relatives) should have an opinion but I think what you want as the actual donor should be paramount. And I know it's very, very difficult to implement that…Are the relatives respecting what the patient wanted? So you can sign a DNR and they have to respect that…I think if you've expressed this is what I want when I die then it should be respected, as would the way you want your funeral and anything else you want doing. It should be the same sort of thing." (B2 – 1 Theatre Staff Nurse)*
- *"I think you've got to respect the wishes of that person. Yeah, you've got to take into consideration the feelings of the family but that person has made that decision for themselves. You'd be doing them a disservice to actually not fulfil what they wanted. It is their right to choose what they want to do. I mean, if they decided to put their body up for research, who are we to question? They've made that decision. The family can't say no to that so why should they be able to say no to organ donation?" (B4 – 1 Theatre Clinical Manager)*

Deemed Consent: Effective?

- *"I can't see how we're ever going to have an opt-out system where the family can't override it…we've always really had real family involvement in after death…I think it's not just changing the way we gain organs it's changing the way in which we think about death and whose body is it. And certainly in this country I think most people believe the body really pretty much belongs to the family once they've died and this is a shift towards it belonging to the state." (AB1 – 4 Consultant in Anaesthetics and Intensive Care)*
- *"I suspect the family will still have the right to refuse so we are no further advanced. Or you will have a battle between doctors and the family potentially. So you might increase organ donations but I think the feel for organ donation would change and it wouldn't be seen as being the gift that maybe it's seen as being now." (AE1 – 1 Consultant in Intensive Care Medicine)*

Initial Observations

- Numerous ethical uncertainties identified
- Enabled aspects of the deemed consent policy to be called into question as to how ethical and moral it is
- Allowed HCPs to position themselves as ‘ethical’ and ‘moral’



- A ‘donation ethics’ emerges – an ethical framework can be observed that surrounds deceased organ donation practices.

Concluding Thoughts: (A) Donation Ethics?

MINIMISE HARMS

RESPECT FOR PERSONS AS INDIVIDUALS AND COMMUNITY MEMBERS

CONFIDENTIALITY

DEMOCRACRY

AUTONOMY

COLLABORATION

FAIRNESS

JUSTICE

EQUALITY

TRANSPARENCY

OPENNESS

ACCESSIBILITY

POWER

ENABLING

FACILITATION

CHOICE

VULNERABILITIES

GUARDIANS

CHAMPIONS

EMPOWER

INFORM

VOLUNTARY

OWNERSHIP