smw · swiss medical weekly

Viewpoint | Published 04 March 2024 | doi:https://doi.org/10.57187/s.3572
Cite this as: Swiss Med Wkly. 2024;154:3572

Introducing “opt out” organ donation in Switzerland: lessons from the UK experience

Jordan A. Parsons

Birmingham Medical School, University of Birmingham, United Kingdom

Introduction

Following the 2022 referendum [1], Switzerland is due to introduce an “opt out” system for organ donation in the coming years. The proposal put to the vote was in response to a 2019 popular initiative that sought to have “opt out” written into the federal constitution. The referendum’s counterproposal made changes such as including a consultative role for the donor’s family. Despite the Referendum Committee recommending “No”, voters aligned with the Federal Council and Parliament in endorsing the change [1]. Whilst finer details of the new system are not yet set in stone, development efforts are underway after the 60.2% vote in favour [2].

Over the coming years, as the new system is designed and implemented in Switzerland, it will be important to draw on the experiences of other jurisdictions. A particularly useful example to look to is the UK, for two reasons. First, it provides a recent example. Second, with the four UK nations having different (albeit very similar) systems, it provides a means of considering a mixture of approaches within a (largely) single culture.

In this Viewpoint, I explore some key elements of the UK “opt out” systems, highlighting those of relevance for consideration as Switzerland moves in this policy direction.

Timing of implementation

An easily overlooked point in the introduction of “opt out” is the timing of implementation. By which I mean specifically how long after the passing of the relevant legislation the system comes into force. With most legislation, this is not a significant concern – it is not uncommon for laws to come into force very soon after completing their journey through the legislature. With “opt out”, however, there is great importance in getting the timing right.

Looking to the UK, it is the example of Wales that is most useful here. Unlike the other UK nations, Wales provided an explicit statutory requirement that there be a period of at least two years between the passing of the law and the coming into force of the new “opt out” system [3]. This was rightly recognised as important in ensuring that there was sufficient knowledge among the population before “opt out” would actually apply to anyone in practice. Whilst there was an inevitable period between the legislation and its implementation in the other UK nations, it not being a fixed requirement did risk poor public understanding of the new systems.

To some degree, Switzerland might be thought of as having a head start on public awareness of its forthcoming “opt out” system. Given the vote, there was a level of awareness associated with the referendum process itself. This, however, cannot be relied upon. First, only a proportion of the population of Switzerland were eligible to vote, and of those only 40% did [2]. Further, of those who did engage with the referendum, we cannot be sure that they followed the result.

It remains, then, that a transitional period after the constitutional amendment is actioned, focused on public awareness, would be beneficial to the Swiss system. This would also strengthen its ethical credentials in relation to the broader importance of public awareness of the “consent” aspect – which I will come to shortly. Whether two years is an appropriate period is a moot point, but certainly provides a starting point.

Applicability

“Opt out” systems tend to limit their reach in certain ways. For example, by excluding children and those with cognitive impairments. Such exceptions are rooted in the principle of respect for autonomy, seeking to exclude from the system’s remit those that we cannot be confident will be aware of or understand the policy and how it might affect them.

Exclusion based on age and mental capacity are relatively straightforward. The design of the “opt out” system can map onto relevant existing legislation, such as what a given country’s healthcare system deems the age of majority for providing informed consent to treatment and how its regulation is designed to protect and promote the autonomy of those with cognitive impairments. There may be some difficulties in navigating the precise framing, but the core intention need not be entirely rethought.

Another common exclusion – and one which raises more difficulties – is based on residency. That is, “opt out” only applying to those who have resided in the country for a given amount of time, as they can then be considered as aware of the system and how to register an objection. Across the UK, this was done by way of a 12-month “ordinary residency” requirement [3]. Other countries, such as Singa-

Jordan A. Parsons
Assistant Professor in Medical Ethics and Law
Birmingham Medical School
University of Birmingham
Edgbaston, B15 2TT
United Kingdom
j.a.parsons[at]bham.ac.uk

pore, instead specify citizenship or permanent residency [4] – something not possible in the UK due to devolution.

Given Switzerland is due to introduce “opt out” by way of amending the Federal Constitution, the option of a citizenship and/or permanent residency stipulation is available. This would, however, exclude a significant proportion of the country’s population given the criteria for both. It may be that an approach similar to the UK nations is preferable, then, striking an important balance between enough of the population coming under the reach of “opt out” and not including those who cannot reasonably be considered to know about the system.

Public awareness

A shift to “opt out” is, at its core, an underlying change to the way consent is understood with respect to organ donation. It makes donation the default, not requiring express consent from a donor to proceed with the procurement of transplantable organs. For this to be considered valid consent, substantial public awareness is required. This is widely recognised in the literature [5, 6], but a particularly clear explanation is provided by Price’s four criteria:

1. Affected persons are aware of the system and the implications of their (in)action;
2. ways of registering an objection (opting out) are easily accessible;
3. sufficient time is allowed for affected persons to make a decision;
4. registering an objection carries no significant consequences [7].

These criteria speak to various elements of an “opt out” system, but centre around the importance of public awareness. With the exception of England [8], the UK nations incorporated public awareness duties into their systems, requiring state actors to make annual efforts. Undoubtedly, the Swiss system will need to incorporate something similar to be considered ethically robust.

Whilst public awareness is essential to any “opt out” system, the high proportion of expats in the Swiss population makes it yet more important. This connects to the question of applicability and whether and when expats will come within the reach of the “opt out” system. Assuming that they will at some point, it is essential that there are *regular* efforts to promote awareness, ensuring that those relocating to Switzerland become aware within a reasonable timeframe.

In terms of the precise activities that might be carried out, examples from the UK include both targeted and general activities. Beyond public advertisements, then, there were campaigns directed at particular societal groups. For example, writing directly to all teenagers ahead of them turning the relevant age for “opt out” to apply. Wales, in particular, has reported in detail on its efforts [9]. Switzerland could benefit from examining these efforts in considering what would be most appropriate to effectively reach the country’s population. On the question of expats in particular, it may be that information about “opt out” is provided upon local registration.

The role of the family

What role – if any – the deceased’s family should have in decisions around organ donation is a contentious matter [10]. Indeed, the response to this question can determine whether an “opt out” system is one that is considered “soft” or “hard”. All four UK systems have incorporated a rather significant family role, such that they effectively hold a veto right even where “opt out” applies [11]. This is, however, a potential weakness, in that it ultimately undermines the purpose of “opt out” by erring on the side of *non*-donation.

The role of the family is something that was built into the Swiss referendum’s proposal as distinct from the original popular initiative, so has clearly been considered already. However, these proposals may prove susceptible to the same shortcomings as the UK systems. For example, the family are required to provide credible evidence of the deceased’s view in objecting to donation [1]. Whether, in practice, this bar is maintained remains to be seen. Further, the family are proposed to hold yet greater power in absentia, in that where there is no family available to consult, donation is not to proceed [1].

Certainly, there are practical – and, arguably, ethical – needs for a significant family role. But where this evolves into an effective veto right, it risks rendering the whole “opt out” endeavour meaningless. Where some sort of assent or consent is still required from the family, there is limited distinction between an “opt out” and “opt in” system in practice. Precisely how strong a line Switzerland chooses to take when developing professional guidance remains to be seen, but a delicate balance must be struck if the system is to have any hope of delivering on its stated goals.

Summary

Getting an “opt out” system right and introducing it appropriately are key to public support and longevity. This is particularly true for avoiding opposition based on fear of pre-death organ acquisition, which led to the Brazilian system being abolished [12]. With so many countries already operating “opt out” systems, Switzerland has the opportunity to learn from these varied experiences. Four key matters ought to be the focus as details of the Swiss “opt out” system are defined.

First, implementation should come after a defined period from constitutional amendment, allowing for extensive public information campaigns. Second, consideration should be given to who is affected by the legislation, paying particular attention to residency requirements given the high expat population in Switzerland – “ordinary” residency may be preferable to permanent residency or citizenship in this context. Third, a commitment to public awareness ought to be in some way entrenched in the new system, ensuring efforts to maintain understanding continue indefinitely and do not peter out in the years following implementation. Fourth and final, the precise role to be played by the family of potential donors should be further explored, seeking to minimise the impact of the so-called family veto while avoiding unnecessary distress and conflict.

Whether the new “opt out” system will increase donation rates in Switzerland remains to be seen. Nonetheless, international experiences – such as the UK’s – should be considered in developing an ethically defensible policy.

Acknowledgements

This work was completed during my time as a visiting Stehr-Boldt Fellow at the University of Zurich's Institute of Biomedical Ethics and History of Medicine. My thanks to the Institute for awarding me the Fellowship, and to its members for interesting discussions during my time there.

Potential competing interests

The author has completed and submitted the International Committee of Medical Journal Editors form for disclosure of potential conflicts of interest. No potential conflict of interest related to the content of this manuscript was disclosed.

References

1. Schweizerische Eidgenossenschaft. 2022. Änderung des Transplantationsgesetzes. Available at: https://www.admin.ch/gov/de/start/dokumentation/abstimmungen/20220515/aenderung-des-transplantationsgesetzes.html
2. Schweizerische Eidgenossenschaft. 2022. Vorlage Nr. 656 Resultate in den Kantonen. Available at: https://www.bk.admin.ch/ch/d/pore/va/20220515/can656.html
3. Human Transplantation (Wales) Act 2013.
4. Human Organ Transplant Act 1987 [Singapore].
5. Saunders B. Opt-out organ donation without presumptions. J Med Ethics. 2012 Feb;38(2):69–72. http://dx.doi.org/10.1136/medethics-2011-100039. PubMed. 1473-4257
6. Veatch RM, Ross LF. Transplantation Ethics. 2nd ed. Washington (DC): Georgetown University Press; 2015.
7. Price D. Human Tissue in Transplantation and Research: A Model Legal and Ethical Donation Framework. Cambridge: Cambridge University Press; 2014.
8. Parsons JA. Deemed consent for organ donation: a comparison of the English and Scottish approaches. J Law Biosci. 2021 Mar;8(1):lsab003. http://dx.doi.org/10.1093/jlb/lsab003. PubMed. 2053-9711
9. Welsh Government. 2018. Human Transplantation (Wales) Act 2013. Report laid before the National Assembly for Wales under Section 2.(3). Available at: https://www.gov.wales/sites/default/files/publications/2018-12/organ-donation-wales-communications-activity-2018_0.pdf
10. Albertsen A. Against the family veto in organ procurement: why the wishes of the dead should prevail when the living and the deceased disagree on organ donation. Bioethics. 2020 Mar;34(3):272–80. http://dx.doi.org/10.1111/bioe.12661. PubMed. 1467-8519
11. Human Tissue Authority. 2023. Code of Practice on the Human Transplantation (Wales) Act 2013. Available at: https://content.hta.gov.uk/sites/default/files/2023-06/Code%20of%20Practice%20on%20the%20Human%20Transplantation%20%28Wales%29%20Act%202013.pdf
12. Csillag C. Brazil abolishes “presumed consent” in organ donation. Lancet. 1998 Oct;352(9137):1367. http://dx.doi.org/10.1016/S0140-6736(05)60767-2. PubMed. 0140-6736