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Assessing deemed consent in Wales - the advantages of a broad difference-in-difference design

As the debate over an English opt-out policy for organ procurement intensifies, assessing existing experiences becomes even more important. The Welsh introduction of opt-out legislation provides one important point of reference. With the introduction of deemed consent in December 2015 Wales became the first part of the UK to introduce an opt-out system in organ procurement.

My article “Deemed consent: assessing the new opt-out approach to organ procurement in Wales” conducted such an early assessment of this.[1] Taking its starting point in important concerns often raised in discussion over opt-out legislation, it identified four key parameters to assess the effects. These are living donor rates, deceased donor rates, donor registrations and family refusals. My article compares these indicators before and after the enactment of the Welsh legislation employing a different-in-different design. In their reply to my article ‘Deemed consent: assessing the new opt-out approach to organ procurement in Wales’ the author offers two interesting critiques. The first pertain to the choice of indicators. They prefer a narrower focus on the effect on deceased donor rates. The second pertain to the choice of data, preferring a time series of Wales to my different-in-different design. Author refers’ mainly to the official Welsh evaluation,[2] a report I also cited in supplement to the NHS Activity Report data I employed. Responding to these critiques provides a welcome opportunity to elaborate the chosen approach.

Broad or narrow assessment

Author claims that my article ‘fails to fully examine the extent to which new legislation has had a positive impact.[3] Authors reason for believing this is stated as follows ‘It is, of course, a good thing that the new system has not damaged the transplantation endeavour, but a worthwhile assessment ought to focus more on whether the Act has met its purpose.’ I agree that the purpose of the legislation is to increase transplant rates. Surely, we are interested in more than whether concerns are realized. We do not pass opt-legislation to avoid concerns associated with such legislation, but to increase the number of organs available for transplants. Of course we should do more than simply check whether things turned out bad. My article does this. For every examined parameter, I assess whether they go up or down. I do not only assess that they did not go down. This would indeed be incomplete, but this is not the assessment conducted in the article.

Does my broader assessment, which focus on a wider range of parameters side-step the main issue? I agree that the purpose of deemed consent is to increase actual transplant rates. I disagree however, that one should infer from this that we would achieve a more complete assessment of the effects of such legislation through a narrower focus on the development of transplant rates. Assessing only the development of the transplant rates for deceased donation would have left us in the dark in terms of what influenced the drop in these. It would also have left us without important knowledge about how deemed consent broadly speaking affected the procurement process. My broader approach allows us to see that the drop was not driven by an increase in family refusal, or a decrease in the number of registered donors. It also provides us with the knowledge, that at

least initially, there was not a drop in living donations, something which is often a reported feature of opt-out systems.[4] Especially given the short time-span of the legislation, something that I highlight as ‘the most important limitation’ of my assessment, it is important to conduct a broader assessment. Both to see whether opt-out legislation negatively affected factors intimately linked with donation rates, and to provide us with insights into factors, which could affect transplantation rates in both the short and the long run. I content then, contrary to author’s claim, that a broad assessment is preferable to understand whether and for what reasons, the Act has met its purpose of increasing transplant rates.

Time-series or difference in difference

The second concern raised by author pertains to which kind of comparison is most suitable for assessing the development. Author prefers a time-series analysis, where the trend in Wales before passing the legislation is contrasted with the post-legislation outcome. In raising this critique, author unfortunately offers a very incomplete description of the analysis I conducted, describing it as a comparison of Welsh data before and after the change of legislation. This is an unfortunate description of my approach. I compare the development in Wales with the UK as a whole in a difference-in-difference design. Thus, I compare Wales where the legislation was changed with broader trends in the rest of the UK, where opt-in policies remained in place. The advantage of such an approach is, that it provides insight into whether the development in Wales reflects a broader trend in the UK or is a Welsh phenomenon. My misgivings about authors description of my approach aside, I agree that it makes sense to also look at the trends leading up to the change of the legislation. Author suggests that family consent rates and transplantation rates are especially important. Given what I argued above I of course agree, and my article examined both parameters.

What does examining the longer trends show? For deceased transplant rates author cites the same stable picture as reported in my article, citing, as I do in supplement to the Activity Report numbers, the official Welsh evaluation.[2] Contrary to what author asserts, I do not find these numbers encouraging. I highlight that this calls for further investigation.

For the family consent rate, I agree that there is something to be gained from observing the longer trend. This reveals Wales to have been catching up. I disagree with author that a measure of moving annual total is most suitable to detect the effect of the legislation. The moving annual total for Q1 2016 includes several months under the old legislation. The measure I employ from the NHS report does not. However, the trend noted by author should encourage our interest in what caused the drop in family acceptance in 2013-2014, and further examine the role of the discussion regarding deemed consent legislation and the associated information campaigns in assuring that it has been rising ever since.

Reflecting on the above, I believe the best approach is one which compares time series from various countries in the UK for a broad set of parameters.

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