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# Opt-in or opt-out: that is not the question

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It has been reported that the Hong Kong SAR Government has been considering opt-out legislation for organ donation. Dr Wing-man Ko, former Secretary for Food and Health, believes that a more active approach is needed.<sup>1</sup> A background information paper was offered by the Food and Health Bureau on 14 June 2017.<sup>2</sup> Although the organ donation rate in Hong Kong increased from 4.60 donors per million population (pmp) in 1996 to 6.30 donors pmp in 2016, the figure remains among the lowest in the world.<sup>3</sup> According to international data in 2016, Spain has the highest donation rate in the world (43.4 donors pmp), while Hong Kong's figure represents less than 20% of that rate.<sup>4</sup>

Hong Kong is now adopting the opt-in system, that is, only those who have given explicit consent will be donors. Other countries such as Spain and Singapore are adopting the opt-out system, that is, anyone who has not clearly refused is presumed a donor. By comparing the data of the opt-in and opt-out countries, some studies show that opt-out consent leads to a relative increase in the total number of organs transplanted,<sup>5</sup> but the findings are inconclusive. As Shepherd et al<sup>5</sup> remarked, "it may be too simplistic to state that the introduction of opt-out consent will increase deceased donation rates". Based on a few important considerations, we do not think it will be helpful to improve Hong Kong's donation rate by changing to an opt-out system.

First, although it is recognised that an opt-out system is likely to bridge the gap between people's intention and their behaviour by removing the need to undertake any action in order to become a donor,<sup>6</sup> it is also recognised that donation rates are multi-causal and that an opt-out strategy may not actually help. For example, Spain's opt-out consent legislation in 1979 did not have a positive influence on donation for 10 years. It has been through crucial organisational changes (such as certain incentives offered to its coordination networks and hospital coordinators) introduced since 1989 that have afforded Spain's success.<sup>7</sup>

Second, in Hong Kong, a Centralised Organ Donation Register (CODR) that allows prospective donors to register their wish of donating organs after death through online registration or by email or fax was set up by the Department of Health in 2008.

The Register is also used by the Organ Donation Coordinators of the Hospital Authority to contact the families of deceased patients as potential donors.<sup>8</sup> There are only nine Organ Donation Coordinators working for seven clusters of 41 public hospitals.<sup>9</sup> A heavy workload and insufficient manpower hinder the effectiveness of donation coordination.<sup>10</sup> As Spain's experience shows, introducing incentive measures and improving existing supportive organisations are essential to the success of its opt-out approach. In other words, legislation on opt-out consent alone is not sufficient to boost organ donation.

Third, an opt-out system may also compromise significant ethical values by failing to respect individual preferences or personal autonomy.<sup>11,12</sup> Importantly, most opt-out countries, such as Spain, have adopted only a 'soft' approach, in which family members are able to veto organ donation even if no formal objection has been expressed by the deceased. As an influential British ethical council points out, the importance attached to an individual's wishes absolutely excludes any consideration of introducing a 'hard' opt-out approach (in which organs would automatically be taken regardless of the families' views or wishes, unless the deceased had explicitly objected during their lifetime) to deceased organ donation, "given the impossibility of ensuring that everyone would be sufficiently well-informed to have the opportunity of opting out during their lifetime."<sup>13</sup> This is to say, changing to a 'hard' opt-out system would be unethical, even for a western individualist society. The reason is that autonomous individual action must be in line with an individual's wishes and such wishes must be based on adequate, rather than insufficient, incomplete, or one-sided, information. Nonetheless, the British ethical council recognises that it is simply impossible for everyone to be sufficiently well-informed to opt out in a 'hard' opt-out system.<sup>13</sup> Accordingly, many countries fall back on a 'soft' opt-out system to secure an individual's own wishes by relying on the family's input so as to fully respect individual autonomy.

Fourth, the issue of public trust is engaged. In the context of Hong Kong, a 'hard' opt-out strategy will inevitably create a situation where donation coordinators and medical professionals are conceived as intervening to 'take' organs rather than facilitating their donation. Under these circumstances, public

trust in the Hong Kong medical system would be significantly compromised. We do not think it wise for society to take this risk at the present time.

Finally, given that some studies have shown that countries that adopt an opt-out approach can slightly increase the donation rate and decrease the refusal rate of family members,<sup>14</sup> should Hong Kong change to a 'soft' opt-out system? This paper argues that this fallback does not work either. It has been the norm in Hong Kong that immediate family members make any decision about deceased organ donation if no wishes have been clearly expressed prior to death. Accordingly, simply replacing our current family-based opt-in way by a 'soft' opt-out system would not significantly change the result because families will continue to make the final decision. Singapore has experienced the effective force of its society's ethical culture around the issue. In 2008, the government revised the Human Organ Transplant Act (HOTA) and clearly stated that "if the patient has not objected to organ donation previously, in accordance to HOTA, the wishes of the patient to donate his or her organ after death must be upheld."<sup>15</sup> Nonetheless in practice, organ retrieval from the deceased in Singapore has still been carried out with appropriate concern for the family's wishes.<sup>2</sup> Indeed, international research has discovered that the next-of-kin has considerable influence on the organ procurement process in both opt-in and opt-out system nations.<sup>16</sup> Changing to a 'soft' opt-out system without successfully gaining the support of Hong Kong families would not be very helpful. Just as Spain's good outcome was achieved primarily through organisational changes and incentive provisions rather than through its opt-out strategy, it might be more productive and ethically pertinent to improve Hong Kong's organisational factors and offer proper incentives to gain the support of both individuals and their families for organ donation.

Some may argue that if an individual has registered in the CODR his/her wish to donate organs, it is violating his/her autonomy if the family veto that wish after his/her death. We think the issue is more complicated than a simple confrontation between respecting individual autonomy versus respecting the family. Autonomy is the capacity not only to set one's own goals to direct one's action, but also to refrain from acting on impulses one may experience if they are incompatible with the goals one has adopted, especially when one has an impulse without being sufficiently well-informed in the first place. The individual may have merely wanted to indicate his/her preference and will not be so minded to have it modified or even overridden by the decision of other family members.<sup>17</sup> In a Confucian-influenced family-based culture like Hong Kong, one's family normally assists an individual's capacity

to exercise autonomy. A shared decisional authority by both the individual and the family is normally acknowledged and appreciated as embodying the naturalness and usefulness of the engagement of immediate family members in a person's biomedical decisions to facilitate, rather than obstruct, that person's autonomy.<sup>18</sup> This is all the more reasonable since the CODR form used in Hong Kong is very simple and fails to provide adequate information and does not request details that are necessary for a truly valid registration or informed consent. It should be recognised that there are intractable practical difficulties to improving this procedure and making it a sound, valid informed consent process that would exclude a family's right to veto: you would need special medical professionals to provide information and answer questions to ensure that the potential donor understands what he/she is consenting to, and under what circumstances and by which death criteria (that are still controversial in the contemporary world) he/she would donate organs. Given that this is highly improbable, a family's right to veto constitutes a reasonable means that largely protects, rather than violates, the individual's autonomy. Compared with medical professionals or other relevant parties, the family is in a much better position to decide whether the request made by the deceased is still valid, whether it has been withdrawn, or is otherwise inconsistent with the deceased's long-standing life goals. This may be why the Hong Kong Legislative Council rightly requires that "the family of the deceased has to sign a consent form to confirm the organ or tissue to be removed for transplant purpose."<sup>19</sup>

Taking all these considerations into account, it is more productive for us to research efficacious and defensible incentive measures that will motivate both individuals and their families than to introduce an opt-out strategy to optimise organ donation in Hong Kong. For example, following Israel, both mainland China and Taiwan have recently decided to incorporate legal conditions that will prioritise a donor's family members for organ distribution: deceased organ donors are honoured and their relatives are given higher priority on any organ transplant waiting list.<sup>20</sup> Such incentives are ethically fitting for Chinese family-based culture and should be studied and adopted to promote organ donation in Hong Kong. Mandated choice is another alternative. In some states of the United States, drivers who wish to renew their licence are required to check a box stating their preferences for organ donation. The renewal application will not be accepted if they fail to comply. We believe that this is a timely option to take as the Hong Kong SAR Government plans to introduce new Hong Kong Identity Cards from 2018: citizens should be asked to indicate their preferences for organ donation. Moreover, to

facilitate communication, respect shared authority and avoid conflict, they should also be required to state if their preferences to donate are known and accepted by their families so as to reduce later family refusal.

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