British Medical Association Cymru / Wales

INTRODUCTION

BMA Cymru Wales is pleased to provide a response to the consultation Proposals for Legislation on organ and tissue donation: A Welsh Government White Paper.

The British Medical Association represents doctors from all branches of medicine all over the UK. It has a total membership of nearly 150,000 including more than 3,000 members overseas and over 19,000 medical student members.

The BMA is the largest voluntary professional association of doctors in the UK, who speak for doctors at home and abroad. It is also an independent trade union. BMA Cymru Wales represents some 7,000 members in Wales from every branch of the medical profession.

This paper has been formulated and agreed by BMA Welsh Council. It has also been supported by the seven Branch of Practice Committees in Wales, these are:

- Welsh Consultants Committee
- General Practice Committee (Wales)
- Welsh Committee for Public Health Medicine
- Welsh Staff and Associate Specialist Committee
- Welsh Junior Doctor Committee
- Welsh Medical Academics Committee
- Welsh Medical Students Committee

RESPONSE TO CONSULTATION QUESTIONS

Persons who will be included in the soft opt-out system

1. The White Paper sets out individuals must have lived in Wales for a sufficient period of time before being included within the soft opt-out system.

a) What factors should be taken into account when determining whether an individual ‘lives in Wales’?

BMA Cymru Wales believes that this is a matter for the Welsh Government to determine.
However, it is imperative that the information clinicians have is reliable and accurate, whatever criteria is decided upon, before they enter into discussions with family members about the wishes of their loved ones to donate.

A number of difficult scenarios can be envisaged in determining whether a person ‘lives in Wales’ – for example; students who have a term-time addresses in Wales; transient communities; homeless individuals; and individuals with no relatives - these will require clarity in order to support clinical decision making.

b) What should that period of time be?

Again, this is a technical question which BMA Cymru Wales is not best placed to respond to. It is essential that everyone who moves to Wales is made aware of the policy, and the means by which they can opt-out if they wish to, we would not think that the time period needs to be overly long. It seems sensible to use existing mechanisms such as the electoral role or council tax records as a means to commence counting any specified time period.

2. Do you agree discussions between clinicians and family in the event of an individual’s death, will identify and safeguard those who lack capacity?

Yes.

The BMA does not believe that blanket exceptions or automatic exclusion of such groups are appropriate but rather that steps should be taken to facilitate individual decision making to the greatest extent possible. Where individuals cannot understand the choice, however, it cannot be presumed that they consent to donation and some provision needs to be made for this by, for example, allowing family or legally appointed proxy decision makers to decide on their behalf.

We believe, that the relevant question here is not whether they have capacity at the time of admission to hospital – many people lack capacity shortly before death e.g. after a road traffic accident (RTA) – but whether they have had capacity at any time since the new legislation was introduced (in order that they have had an opportunity to object). This may require wider liaison, such as with the patient’s GP and other care providers in addition to the family and the team treating the patient immediately before death.

3. Do you agree that the soft opt-out system for Wales should only apply to persons aged 18 years and over? If not, why?

The BMA believes that an opt-out system should apply to those aged 16 years or over. This is the age at which there is a presumption of competence. Below that age either the consent of the young person and/or parental consent should continue to be sought.

However, from a young age education and awareness about organ donation and publicity are extremely important. The need to maintain the UK Organ Donor Register (ODR) – in order that those under the specified age limit who wish to donate are not precluded from organ donation - is also important here.

In meetings and discussions with fellow stakeholders the issue of an upper age limit has arisen. This is not something we would support.

**The operation of the soft opt-out system for Wales**

4. Do you agree with the retention of the existing Organ Donor Register to be operated in conjunction with the soft opt-out system?

Yes, we strongly support the retention of the UK Organ Donor Register (ODR).
Particularly, we feel in order to ensure that Welsh people who die outside of Wales, and are therefore not subject to any Welsh Government legislation for soft opt-out, are still able to donate their organs by virtue of maintaining their name on the UK ODR.

BMA Cymru Wales not only supports the retention of the ODR, we feel it is also offers the most appropriate means of introducing soft opt-out for organ and tissue donation in Wales. Please see response to question 5b below.

There is also the opportunity here to enable those who wish to opt-out of donating certain organs, but not all, to register which organs they wish to donate on one register.

However, there is a risk that the same individual could be on both the UK opt-in register and the Welsh opt-out register, mechanisms to avoid this need to be devised but also a mechanism to ensure that when it does occur everyone involved clearly knows how it will be managed / what protocol to follow to resolve it.

5. In relation to the record keeping options for the soft opt-out system –

a) Which of the suggested options do you prefer? (See paragraph 56 of the White Paper.)

Please see answer to question 5b below – we believe that there is a fifth option, legal architecture allowing, which should be explored.

We would not support option D. Whilst we would encourage GP practices, and hospitals, to display information about organ donation and have information available about how patients can sign up to the UK organ donor register or opt out of a Welsh register, we would have concerns about GPs being required to seek the views of all their patients or maintaining records. This would take up valuable time in consultations and may cause anxiety among patients who are already concerned about their health.

In regards to option A – a register for Wales of persons who have not objected, and a register of persons who have objected – initially appears relatively sensible in terms of safety assurance - however, it would not be difficult to envisage a situation whereby a person finds themselves on both registers and this would do nothing to contribute to creating a society in which donation is the default position. For this reason we would not support Option A.

Option C seems to be the most appropriate of the four options (if a new register is to be established).

In terms of record keeping more generally we would welcome more detail or proposals on cross-border issues, of which there will be many: for example, if someone dies in an English hospital with which a Welsh Health Board has a contract to provide certain specialist procedures / care – would there be access to any Welsh register to individuals outside of Wales in such circumstances?

b) Are there other options you feel would provide an effective and secure system?

Yes. We would like to propose use of the UK Organ Donor Register in bringing about this change; this is how we envisage that it might work:

The names of everyone in Wales who have not registered their objection (opted-out) are added to the existing UK ODR. That an indicator is used on the Register to clearly show that those individuals are resident in Wales and thus fall under any Welsh Government policy - if they happen to die in Wales.

The basic concept here is that there would continue to be only one register which is available throughout the UK; the UK ODR. It would register the wishes of Welsh residents who die in Wales differently to everyone one else – i.e. by virtue of the fact that they either have or have not opted out of the Welsh Governments policy on donation.
The ODR would need to be modified to take account of the change in policy in Wales to a system of soft opt-out. For example, it would need to account for any subsequent change of mind after an individual in Wales opts out.

There would need to be some mechanism – e.g., date of entry to register – to indicate which of those on the register are there because of the opt-out system and which have actively added their name through joining the ODR. As opting into the UK ODR would automatically register you as a donor across the UK (including in Wales, irrespective of any national policy on opt-out) this is not the case the other way around. This means that only those Welsh residents who have signed up to the ODR would be legally able to donate if they died outside of Wales.

If people who are placed on the ODR register as a result of the new opt-out system in Wales also wish to donate if they die in England, they will still have to make this known to the UK ODR. Clear and continual publicity and advertising will have to play a central role here. By pursuing this option there is already an established method for registering individual wishes in relation to donating specific organs but not donating others.

We believe that the Welsh Government should explore this option as a means of maintaining records.

6. What is the role of the family in safeguarding the wishes of the deceased?

Central, especially when talking to clinicians. Which is why the importance of talking to relatives and those close to you about donation should be a central message in the publicity surrounding the implementation and ongoing operation of this policy.

A key problem with the current system is the relative refusal rate, which stands at around 40%. The difficulty is that where, as in the majority of cases, relatives do not know what the individuals wanted, they frequently, and understandably, opt for the default position which is not to donate. This issue would be addressed by the introduction of a soft opt-out system where an individual’s wishes would now be clarified i.e. they will have decided to opt-out – or remain as an organ donor.

It is worth adding here that that the central role which the family plays in ‘soft’ opt-out is as an added safeguard. The family will be asked if they are unaware of any unregistered objections so that if the individual did not wish to donate but had not got around to formally opting out, this information can be passed on and the individuals’ wishes respected.

Making donation the default position reflects a positive view of donation, and mirrors the very strong support for it within society, with donation becoming to be seen as the norm, rather than the exception.

While relatives would still be consulted under the proposed system, they will more likely be aware of the deceased person’s wishes - a successful opt-out system depends upon high profile publicity informing people that donation is the default position and encouraging people who do not wish to donate to formally register their objection. As a result, discussions within families are more likely to take place and those who have reservations about donation are likely to register their objection. In most cases, therefore, families will be aware of their relatives’ wishes in relation to donation, allowing for better informed decision making, where this becomes necessary in the future.

Implementation

7. How can the Welsh Government ensure that the public awareness campaign is effective?

Publicity, dialogue and full public awareness are the biggest factors to the successful move to a system of soft opt-out.
There needs to be 100% public awareness of the change from opt-in to opt-out. This requires a long lead time to implementation and the use of every possible resource and communication tool and in multiple languages (including braille and sign) in order to reach all corners of Wales and all sections of society.

The publicity, information and dialogue behind this change needs to be fully and appropriately resourced, there is no doubt this will require dedicated investment.

It is vital that this publicity starts at school to get the issue of donation into the public consciousness and to ensure people – especially young people - know that they have a choice to make; this will also encourage dialogue with parents and families at home.

It is also important that high level publicity across the whole of Wales continues after implementation, to encourage continuing awareness of what will be a permanent system for Wales.

It will need renewed ideas on how to ensure that donation, and the choice individuals have to register their objection, becomes an embedded part of the Welsh identity and part of what it means to live in Wales.

Publicity requires imagination and new and different ways of communicating – including alongside the traditional mechanisms using concerts, sporting and cultural events, popular culture, social media, industry, agriculture, membership and professional organisations etc.

By no means will this be a small endeavour, and its importance should not be underestimated if the scheme is to succeed and gain the confidence of the public and the professionals.

8. The Welsh Government would welcome your views on the potential impact of the proposed soft opt-out system for the Welsh Language, race, faith, disability, age, sexual orientation, gender, gender reassignment, marriage or civil partnership.

A lot of work has been done to scope the impact of opt-out, and the issue of donation itself, on many of these areas. From initial research it seems that cultural issues can be important influencing factors when making a decision about organ donation, to a greater extent than faith and belief systems for example.

Campaigns and publicity should target specific hard-to-reach groups or communities as some communities have higher incidences of certain diseases.

Data relating to organ donor waiting lists and organ donors highlights significant disparities between ethnic groups. For instance, UK data shows that people of South Asian (Indian, Pakistani, Bangladeshi or Sri Lankan origin) or African-Caribbean descent are three to four times more likely than white people to develop end-stage renal disease, largely because of the higher prevalence of type 2 diabetes. UK data shows them to make up 23% of the kidney waiting list but 8% of the population. A further concern is that only 3% of donors are from these communities.

UK Potential Donor Audit shows a 32% family refusal rate for White families and 74% refusal rate among non-White families

A long-term approach could be employed not only to promote awareness / increase donor rates but to also use public health and preventive strategies to decrease the number of ethnic minority patients, and any others identified, from requiring a transplant.

As noted above publicity and information should be available in different languages and different formats.

We do not believe that age, sexual orientation, disability, gender, gender reassignment, marriage or civil partnership should be a barrier to donation.

1 http://www.gmc-uk.org/static/documents/content/Gurch_Randhawa.pdf
Useful information on faith and religious beliefs is available on the UK transplant website: http://www.uktransplant.org.uk/ukt/how_to_become_a_donor/religious_perspectives/leaflets/summary_leaflet.jsp

9. The Welsh Government has asked a number of specific questions; if you have any related issues which have not been specifically addressed, please record them here.

The BMA has been calling for several years for a change to an opt-out system for organ donation. This became BMA policy in 1999 and was reaffirmed in 2006 and 2008 and 2011. The BMA has always argued that introducing an opt-out system is one part of a broader plan to improve donation rates. We are supportive of the Welsh Governments White Paper and pleased that Wales will be once again taking a lead on such an important issue. That said, it is absolutely imperative to get this right, as we have mentioned in answers to the questions above - publicity, communication and information are paramount to successfully bringing about a positive change in organ donation rates.

Regarding the consultation and the amount of information in the public domain, we would welcome more detail on the role of clinicians / the impact the changes may have on healthcare professionals. This would be especially useful, for example, in relation to talking to relatives, and in determining mental capacity as specified in this consultation document.

We would also like to see further detail on how this policy is intended to fit in with other measures to promote and raise awareness of organ and tissue donation – in our view, this is just one of a raft of initiatives which should be employed to promote awareness and uptake of donation.

Consideration should also be given to what will happen as new forms of donation are found – such as face or limb donation. For example should an opt-in system continue to operate for these new forms of donation? This is an important consideration in any move to opt-out, especially as complicating the policy may encourage more people to opt-out of donation entirely. We have previously argued that face donation (or other new types of donation) should continue to be based on an opt-in system with consent required from the donor while alive or the family after death. Welsh Government legislation may therefore need to contain provision, such as a Regulation making power, in order to exclude certain organs from the opt-out system.

Importantly - and fundamental to the operation of an opt-out system - the issue of capacity in NHS Wales also needs to be considered. There are a number of questions which need answering in relation to this – can NHS Wales cope with an increased number of donors? Do we have the network, infrastructure and number of healthcare professionals in place to support this policy? Are there enough ITU beds? Are tissue retrieval teams located in the best possible sites to enable access to all hospitals in Wales within one hour? And will performance / success be monitored - and if so, how?