

Health and Social Care Committee

Meeting Venue:
Committee Room 3 – Senedd

Meeting date:
7 February 2013

Meeting time:
09:00

Cynulliad
Cenedlaethol
Cymru

National
Assembly for
Wales



For further information please contact:
**Policy: Llinos Dafydd / Legislation: Sarah
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Committee Clerk
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Agenda

1. Recovery of Medical Costs for Asbestos Diseases (Wales) Bill : Consideration of Key Issues

On the basis of the resolution of the Committee passed at the meeting on 30 January 2013, in accordance with Standing Order 17.42(vi), the Committee will consider this item in private session.

2. Introductions, apologies and substitutions

3. Human Transplantation (Wales) Bill: Stage 1 – Evidence session 8 (10.00 – 10.45) (Pages 1 – 3)

Patient Concern
Joyce Robins

Break (10.45 – 11.00)

4. Human Transplantation (Wales) Bill: Stage 1 – Evidence session 9 (11.00 – 12.00) (Pages 4 – 9)

Rev. Aled Edwards, Chief Executive, Cytûn–Churches Together in Wales and
Secretary, Inter–Faith Council for Wales
Geraint Hopkins, Policy Officer, Cytûn–Churches Together in Wales
Saleem Kidwai, Muslim Council of Wales

Rev. Carol Wardman, Bishops' Adviser on Church and Society, Church in Wales
Stephen Wigley, Methodist Church in Wales

5. Discussion of Business Committee's letter about committee timetables (12.00–12.20) (Pages 10 – 16)

6. Papers to note (12.20–12.25) (Pages 17 – 21)

7. Human Transplantation (Wales) Bill: Stage 1 – evidence session 10 (13.30 – 14.15) (Pages 22 – 23)

Professor John Saunders

HUMAN TRANSPLANTATION (WALES) BILL

From Joyce Robins, Co-director Patient Concern

Introduction

Patient Concern is an independent voluntary organisation set up 13 years ago with the aim of promoting choice and empowering patients. Our core principle has always been active informed consent applicable in any medical context. Joyce Robins was one of the founders and has been Co-Director from the beginning.

Consultation Response

The main change to be brought about by the planned Bill is the concept of ‘deemed’ consent. Deemed is a somewhat archaic word normally meaning ‘consider’ or ‘regard as’ and is absent from common vocabulary. It has presumably been chosen to avoid the term ‘presumed’, which has attracted much criticism. However it still means ‘pretend’ consent i.e. it is pretending that a patient has agreed to donation when they have done no such thing. In no other walk of life is the absence of refusal regarded as consent.

We consider the principles underlying this Bill to be unethical and unacceptable.

All the major studies of the organ donation system, including the Welsh Assembly’s own health committee (at which Patient Concern gave oral evidence), once they had considered all the evidence in depth concluded that the opt out system was the wrong way to go. They found no causal link between a change in the law and rising donation rates and decided that there were far more effective ways of increasing the donation rate. In fact, they considered that changing the law would only distract from the measures that need to be taken to improve the infrastructure so that real change is possible. The measures suggested by the ODTF are now on line to deliver a 50% increase by early this year, increasing to 60% by 1216-17, without spending millions on changing the law.

Opting out is a fundamental departure from the UK norm and our work with patients shows that, as a concept, it is poorly understood. The idea that any amount of publicity will ensure that everyone fully understands their options and the need to exercise them is fanciful. The experience of uploading summary care records under an opt-out system illustrates this point. When Patient Concern opposed this system we were assured that the blitz of information would be such that everyone would know and understand the changes. Later reports showed that in spite of all the publicity (including a letter to every household) most people had no idea that it had happened. The result is that millions of records have been uploaded without patients’ knowledge or consent.

This belief in a ‘silver bullet’ approach to solving the organ donor shortage has the potential for a number of unintended and unwelcome results. It is no longer honest to talk about ‘donation’ in the context of this Bill. A donation is a gift, willingly given,

and that cannot be assumed under these proposals. If families feel that they have no real say in what is happening to the body of a loved one, even though that person has not made a conscious choice, lasting damage could be done to the whole aura of the transplant programme.

It is important to remember UK history, which has involved major scandals involving organ removal without permission. This brought into being the Human Tissue Act 2004; its whole purpose being to ensure that consent is a positive action. Its Code of Practice spells this out. Presumably the Code will now be rewritten to take this right away from Welsh people. We consider this a backward step.

Memories may have dimmed but it would only take a couple of errors, where it could be shown that organs had been taken against the wishes of the deceased, to reawaken them and cause a media firestorm which could damage the whole transplantation process. Alder Hey set back organ donation in the UK by ten years and is one of the reasons that our transplant rate is so poor. We should remember that 2010 mistakes on the organ donor register, ignoring exclusions made by some donors, achieved global publicity. More publicity of this type could cause a serious backlash.

One of the fundamental beliefs behind the legislation is that this step will ensure that people talk more about the subject within their families and make their wishes known. We would suggest that this is a pious hope, unlikely to be realised. The death taboo is still strong – it is a subject that many people cannot and will not consider. Almost everyone cares what happens to their property in the future, yet only 30% of us make a will. This is a parallel with the proportion of apparently willing people who sign the donor register.

There can be no ‘full involvement’ of families once the right of refusal is taken from them. Refusal at the bedside among ethnic minorities is currently 75%. There is a real danger that an element of coercion is being introduced if they are then forced to justify their belief that this is not what their loved one wanted while someone – there is no explanation of who is to judge – ‘assesses’ the evidence. The system where a trained counsellor can take time to help the family reach the decision that is right for them is a distinctly preferable scenario to introducing legal obligation.

There may be many reasons for the disparity between the numbers of those who profess willingness to donate in a poll and those who sign the register – one being whether a ‘yes’ vote in the street reflects reasoned judgment taken after consideration. We note that mandated choice (far more likely to be informed choice) was the favoured route chosen by Welsh people in the early consultation but this was hastily abandoned as being too difficult. The simple solution of giving every patient an opportunity of opting in or out any time they access any form of health care – just as routinely as we record our next of kin seems a simple and obvious solution.

The implication that only a change in the law would suffice is simply spurious and smacks of political opportunism.

14 January 2013

Agenda Item 4

Health and Social Care Committee Human Transplantation (Wales) Bill HT(Org)9 – South Wales Jewish Representative Council

My name is Stanley Soffa. I am chairman of the South Wales Jewish Representative Council and in submitting this document I am not expressly putting forward the opinion of the Jewish Community in South Wales because organs are donated by individuals and not by organisations, whether or not they are Jewish, but I hope that my comments will be of assistance.

Since the summer of 2012 I have been involved in making submissions on behalf of the Jewish Communities of South Wales and with Rabbi Rose of Cardiff United Synagogue attended a consultation event on the 6th August following which we were invited to a meeting with members of the Medical Directorate in October 2012. Later that month Lisa Gerson of Cardiff United Synagogue and I attended a meeting of the Welsh Assembly's Faith Communities Forum chaired by the First Minister where I put forward the Jewish perspective and in November we, together with Rabbi Rose, had a meeting with Cognition.

I do not intend repeating what was said on these occasions but lest it be thought that there has been a change in our approach I would specifically refer to two documents provided to the Medical Directorate, one from the Chief Rabbi and the other from the Board of Deputies. Both pre-date the publication of the Bill but the former shows the approach of those members of the Orthodox community for whom Lord Sacks is currently the Chief Rabbi whilst the latter tries to represent all strands of Judaism in the United Kingdom.

Judaism has always accepted and put great emphasis on our duty to save the life of another and this was reiterated in a statement issued by the current Chief Rabbi in January 2011 when he said

"A living person may donate an organ to save someone else's life. This is not only permitted but also actively encouraged, provided that in doing so the donor is not putting his own life at significant risk.

With regard to donation after death, in principle Halacha (Jewish Law) permits such donation provided that the organ is required for an immediate transplant and not for research".

We are therefore encouraging members of the Jewish community to discuss their wishes regarding organ donation and endorse paragraph 43 of the Explanatory Memorandum of 3 December 2012 when it states that "telling close family about wishes relating to organ donation will be one of the key messages of the education campaign which will accompany the new legislation, since uncertainty about what their relative would have wanted is what prevents many families engaging with the organ donation process. This then results in healthy organs being lost to a potential recipient".

However, where organ donation after death is made in conformity with Jewish practice, the obligation ("*mitzvah*") to perform an act of "*pikuach nefesh*" (saving a life) rests with the family of the dead person and so a Jewish perspective is that presumed consent diminishes the altruistic gift essence of organ donation and is

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perceived to diminish the status and respect with which the body / body parts are held after death.

The definition of “death” has been raised in each of the meetings I have attended and is of importance to many members of the Jewish faith for in the Chief Rabbi’s statement is the following

“In our discussion with medical professionals involved in the field it has become clear that organs are taken from people after death in two different scenarios. Either they are taken after irreversible damage to the brain stem, or after failure of the circulatory system (in common parlance described as “when the heart beat has stopped”). Both of these scenarios lead to respiratory failure (“when breathing has stopped”), and respiratory failure is an important factor in the definition of death in Halacha. There is a view that brain stem death is an acceptable Halachic criterion in the determination of death. This is the view of some Poskim (Halachicdecisors). However it is the considered opinion of the London Beth Din in line with most Poskim worldwide, that in Halacha cardio respiratory death is definitive.

Hence, in view of this, and of the significant Halachic issues relating to the procedure of the donation process itself, we believe that it is imperative that a competent Halachic authority should be consulted by families who find themselves involved in such discussions”.

Consequently, the preferred organ donation system is that families, including Jewish ones, should be able to consider and reflect, consult religious authorities if they so wish, and if they feel appropriate, give consent.

There is no definition of “death” in either the Bill or the Explanatory Memorandum of 3 December 2012 and this raises concerns. There is assistance regarding the role of the next of kin and careful consideration has been given to the wording of both documents to try and ascertain whether the concerns expressed in the meetings have been resolved.

Two paragraphs appear relevant. At paragraph 42 of the Memorandum it is stated that “under the new arrangements, very little will change in practice because the next of kin will still be asked to confirm details about the deceased’s health and lifestyle which might not be contained in their medical records and which could affect their suitability as a donor.” This clearly relates to suitability. It then refers to the separate issue of “consent” by confirming that “it is for the deceased to decide whether to opt in, opt out or have their consent deemed. The wishes of the deceased, whether it be through deemed or express consent should be made known to the family by NHS staff as part of the discussions. The legislation provides families with the right to provide information about whether the deceased would not have consented to their consent being deemed. Families will also continue to have an involvement in the process at a practical level”.

Paragraph 42 has to be read in conjunction with paragraph 44. This is intended to assist in understanding the role of the next of kin. Various scenarios are set out, the first of which relates to deemed or presumed consent and again confirms

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that “the deceased’s consent to donation will be deemed because they had the opportunity to express a wish not to be a donor (opt out) but did not do” and continues “However, the next of kin will be able to say whether they have any information that would lead a reasonable person to conclude that the deceased person would not have consented. This could include, for example, where the deceased had ever discussed the matter with them and expressed a view to the effect that they did not want to be an organ donor. Section 4(4) of the Bill provides that any person in a qualifying relationship, as set out at section 17(2) will be able to provide this information. It is not the intention to prescribe the type and quality of information which will fulfill this requirement, since this will be a matter of judgment in each individual case. However, examples of evidence could include details of conversations with the deceased which a person could reasonably believe took place; conversations which can be verified by another person; or other information which could be accepted as reasonable” but stresses that “in the context of providing this information, it is, as a matter of law, the wishes of the deceased which are relevant”. This is repeated by stating that “Where relations do not produce any information about the wishes of the deceased, then they will be in the position of knowing the deceased had not opted out, and had made no further wishes known. In these cases, the default position is that the deceased was in favour of donation and, as a matter of law, the deceased’s consent is deemed.”

It may be that our concerns are satisfied because paragraph 44 does contain this proviso “However this does not mean organ donation will automatically proceed as there will then be a discussion with the family about the donation process, including the medical history of the deceased. Clinical teams also have a responsibility to be sensitive to the views and beliefs of the surviving relatives in accordance with good practice guidance. This means clinical teams would not add to the distress of families by insisting on donation. It is important to be clear, however, that families do not have a legal veto because the law will recognise the deemed consent of the deceased as having precedence”.

It is further noted that in a “frequently asked question” section on the Welsh Assembly website the following paragraph is included under the heading “will there be a role for the family of the deceased in deemed consent cases?”

“Those close to the deceased therefore do not have a legal right to overrule the decision of the deceased to have their consent deemed. Clinical teams will nevertheless have a duty of care towards the family members and if there are very strong objections or distress then organ donation will not go ahead”.

This wording is different to that in the December 2012 Explanatory Memorandum as it refers to the clinical team having a “duty of care towards the family members’ and “if there are strong objections or distress, then organ donation will not go ahead” and it would be helpful to everyone if the wording in all published documents was identical but in a press release when laying the Bill before the Assembly the Health Minister, Leslie Griffiths, said, “*the role of the family is critical in informing the final decision on what happens to their relative’s organs. The wishes of the deceased are paramount and the vast majority of the people of*

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Wales do expect their wishes to be what really counts. For that reason, as is the case now, the family has no legal right to veto, but in practice a clinician would never add to their distress by insisting on donation". So according to the Health Minister whilst the Bill does not legally allow the family to have a legal veto the clinical team will, in practice, not insist on removal and, if she is correct, it seems that this will apply in situations where a deceased has decided to opt in.

It is therefore possible that our concerns whilst not overcome by the wording of the Bill might be covered by the extracts from the Explanatory Memorandum and Questions and Answers BUT the position of the Jewish Community is that stated in the Board of Deputies submission namely submission "organs are donated by individual Jews not by Jewish organisations" and perhaps I will change this to read "in Wales organs are donated by individual Welshmen and Welsh women and not by the Welsh Government".

11 January 2012

HUMAN TRANSPLANT (WALES) BILL

Like our Roman Catholic counterparts, we, as Bishops of the Church in Wales, would like to bring the following points to your attention regarding this Bill.

1. We strongly support organ transplantations. We see such gifts to others as the greatest gifts that can be given to other human beings. The Church in Wales was consulted and involved in producing the NHS Blood and Transplant leaflets encouraging organ donation from a Christian perspective. We therefore support the Heart to Heart campaign to encourage people to sign the donors' register.
2. However, a gift by definition is a voluntary donation by one person to another – and therein lies the difficulty we have with this Bill. Deemed or presumed consent is neither a gift nor a consensual act. It assumes that if you have not opted out of organ donation, your organs can be used after death. We cannot see how a failure to opt out can be interpreted to mean consent to the transplantation of organs. It turns the definition of donation on its head.
3. Such a Bill as this changes the relationship between individuals and the State, between doctors and their patients and raises a question about individual human rights.
4. The Welsh Government believes that by allowing “someone in a qualifying relationship to the deceased immediately before death to provide information that would lead a reasonable person to conclude that the deceased would not have consented” is allowing relatives a say and is a soft out option. That is at variance with its previous statements

regarding a soft out option where relatives could veto transplantation where someone had not opted out. This could potentially lead to very difficult encounters between relatives and medical staff.

5. During the consultation period, most of the reactions received were negative in character which the Government has decided to ignore, attributing it to an orchestrated campaign. In 2008, a UK Task Force as well as the Assembly's Health Committee rejected such an approach. Given the fact that Wales has seen a 49% increase in donation rates since 2008, encouraging people to donate would seem to be a better way forward.
6. It is arguable that countries which have such a scheme as is proposed (e.g. Spain) have seen an increase in donors only when transplantation services have been vastly improved.
7. We would be pleased to appear before the committee to present our views on this matter during the scrutiny stage of the legislation.

The Most Rev'd Dr Barry Morgan
Archbishop of Wales
On behalf of the Bench of Bishops of the Church in Wales

Agenda Item 5

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Committee Chairs
National Assembly for Wales
Cardiff Bay

30 January 2013

Dear Chair

The Business Committee has discussed the timetabling of committee meetings on several occasions over the past year. At our last meeting we discussed the attached paper which is a proposal to include the Public Accounts and Finance Committees in a rotation with the five scrutiny committees who meet weekly. This would mean that each committee would meet for half a day each week - either Wednesday morning, Thursday morning or Thursday afternoon. Tuesday morning would be available if any of the six committees who meet weekly plus the Finance Committee needed to have any additional meeting time.

Before we reach a decision on this, the Business Committee would like to hear your views on the proposals. I would also like to invite you to discuss the issue with your committee members as well.

So that we can make a decision in good time for the timetable for the summer term to be agreed, please could you let me have your response by Wednesday 13 February.

Rosemary

Rosemary Butler AM, Presiding Officer

Bae Caerdydd
Caerdydd
CF99 1NA
Cardiff Bay
Cardiff
CF99 1NA

To: Business Committee

From: Business Committee Secretariat

Date: January 2013

Committee Timetable

Introduction

1. Following the attendance of the Chair of the Public Accounts Committee last week, the Business Committee requested information on the practical implications of the proposal he put forward.

The Chair's proposal

2. Darren Millar's proposal is that the PAC and the other principal scrutiny committees should be treated equally in terms of timetabling. Specifically, he proposes that there should be three main slots - Wednesday mornings, Thursday mornings, and Thursday afternoons - through which the PAC and the five subject committees would rotate in groups.
3. Tuesday mornings would be available for any committee to use should their workload make this necessary.

Current arrangements

4. The current committee timetable allows the PAC to meet weekly on Monday afternoons and Tuesday mornings.
5. Following discussion at the start of this term, the Business Committee considered an alternative arrangement, to be put to the Chair of the PAC, which would timetable the committee for weekly meetings on Tuesday mornings and fortnightly on Thursday afternoons.¹ This would generate a timetabling clash for the Chair on those Thursday afternoons as he is also a member of the Health and Social Care Committee.
6. All other options for accommodating additional time for PAC within the current Wednesday/Thursday timetable of committee business result in multiple membership clashes.

¹ This would mean PAC met at the same time every other Thursday afternoon as the Health & Social Care Committee and the Enterprise & Business Committee

The impact of the proposal on the committee timetable

7. Implementing the proposal would reduce the scheduled meeting time available to each of the five large scrutiny committees by a third, to 1 day per fortnight, compared to 1½ days per fortnight at present.
8. To compensate in part for this loss of time, the proposal is that Tuesday mornings would be available for any committee to use as needed. The only committee meeting routinely on a Tuesday morning would be the Petitions Committee (which meets fortnightly). Membership clashes exist between the Petitions Committee and Health & Social Care (1 member), Environment & Sustainability (2 members), Communities, Equalities & Local Government (1 member) and Enterprise & Business (1 member). The two committees which do not have membership clashes with Petitions (PAC and Children and Young People Committee) cannot meet at the same time as each other because of membership clashes.
9. Taking these factors into account, Annex 1 includes a possible rota for Tuesday mornings that would avoid any membership clashes. For most committees this would make a slot available every 4 weeks. Most committees would, therefore, have access to less time overall than at present.
10. Alternatively, time on Tuesdays could be made available on a 'first come, first served' basis. How workable such an arrangement would be would depend on how often and widely the slot was used. If relatively limited, membership clashes and competition for the time would be infrequent. If there were high demand for the slot, clashes would be more frequent and, conceivably, some committees could find the slot unavailable altogether.
11. Provided that the Finance Committee is included in the cycle along with the PAC and five subject committees, a rotation system around the three slots on Wednesdays and Thursdays can be done without generating any membership clashes. There are two possible permutations which are shown in Annex 1.

Current use of scheduled time by committees

12. Reliable data on the time actually used by committees for all formal and informal activity² undertaken by committees in their timetabled slots are not available. It is possible to obtain information on the number of slots that have been utilised in some way. Looking back, during the 2012

autumn term, there were 15 available slots for each subject committee³. Of the 75 in total, 63 were used for committee business. This varied between committees with Enterprise & Business, Environment & Sustainability and Health & Social Care undertaking formal or informal committee business in 14 of their 15 slots. The equivalent figure for the Children & Young People and Communities, Equalities & Local Government Committees was 10 out of 15. The PAC met 13 times out of a potential 20.⁴

13. How significant the impact of the reduction in time would be clearly depends on the future workload and priorities of those committees. It is always going to be difficult for committees to control the level of legislative activity since this lies with the Government and the Business Committee.

Other implications

14. The model proposed would impact on committees' ability to carry out informal activities such as meetings outside Cardiff and visits. A regular Thursday slot enables committee activity to be planned with minimal impact on other Assembly business and constituency time.
15. Similarly, the proposal would largely prohibit committees from conducting 'an inquiry in a day', whereby a large number of evidence sessions are scheduled in a morning and afternoon on the same inquiry.
16. The model might also have an impact on legislative timetables depending on how frequently committees rotate their slot.
17. It is assumed that the Constitutional and Legislative Affairs Committee would continue to meet in its Monday afternoon slot. Given the nature of the deadlines on legislation it would be disruptive for CLA to take part in any rotation which means them meeting on different days.

Summary and next steps

18. Business Managers are invited to consider:

- The proposal would reduce the scheduled time available for the five large subject committees;

³ taking Wednesday AM, Thursday AM, Thursday PM as separate slots. Thursday meetings which started before 12:00 and finished after 13:00 are considered to have required use of two separate slots.

⁴ 10 of PAC's potential 20 meeting slots took place on Monday afternoons.

⁵ For example, the Health and Social Care Committee has done one-day inquiries into venous thrombo-embolism prevention (on 24 May 2012) and Still Births (on 28 June 2012).

- Use of Tuesday mornings would compensate partially, but not entirely, for that loss of time;
- How efficiently Tuesday mornings could be utilised would depend on the level of take-up;
- The impact of the reduction in scheduled time would vary from committee to committee. Some committees currently use nearly all of their scheduled slots but others do not;
- The proposal could be put into practice without any membership clashes occurring on Wednesdays or Thursdays.

19. Should the Business Committee wish to pursue the proposal, our advice would be to consult with all other committee Chairs and Members generally.

Annex 1

There are two arrangements by which membership clashes can be avoided within the PAC Chair's proposals.

Arrangement 1:

- Group 1- Enterprise & Business Committee; Health & Social Care Committee; Finance Committee
- Group 2- Public Accounts Committee; Environment and Sustainability Committee⁶
- Group 3- Children and Young People Committee; Communities, Equalities and Local Government Committee

Arrangement 2:

- Group 1- Children and Young People Committee; Communities, Equalities and Local Government Committee; Environment and Sustainability Committee
- Group 2- Enterprise and Business Committee⁷, Public Accounts Committee
- Group 3- Health and Social Care Committee; Finance Committee

In both arrangements, groups would rotate between Wednesday mornings, Thursday mornings and Thursday afternoons. The frequency of rotations is not critical to the effectiveness of the model- i.e. it could be weekly, termly, or any other period of time considered appropriate by the Business Committee, but a weekly rotation could affect legislative timetables and Members ability to plan other activities.

Example timetable for either arrangement:

	Wednesday AM	Thursday AM	Thursday PM
Spring Term (or Week 1)	Group 1	Group 2	Group 3
Summer Term (or Week 2)	Group 3	Group 1	Group 2
Autumn Term (or Week 3)	Group 2	Group 3	Group 1

Committees would also be able to make use of Tuesday mornings. Most committees have membership clashes with the Petitions Committee, which meets fortnightly on a Tuesday morning. The two committees which do not have membership clashes with Petitions (PAC and Children and Young People

⁶ Under arrangement 1, the Environment and Sustainability Committee could additionally meet in group 3's scheduled slot

⁷ Under arrangement 2, the Enterprise and Business Committee could additionally meet in group 3's scheduled slot

Committee) cannot meet at the same time as each other because of membership clashes. On average, most committees⁸ could guarantee being able to use one Tuesday morning every 4 weeks without any membership clashes.

Example arrangement for using Tuesday mornings:

Week 1	Petitions Committee, Children and Young People Committee
Week 2	Enterprise and Business Committee, Health and Social Care Committee
Week 3	Petitions Committee, PAC
Week 4	Children and Young People Committee; Communities, Equalities and Local Government Committee; Environment and Sustainability Committee

⁸ An exception to this is the Children and Young People Committee, which could potentially meet on a Tuesday morning every 2 weeks, under this model.

Health and Social Care Committee

Meeting Venue: **Committee Room 1 - Senedd**

Meeting date: **Wednesday, 16 January 2013**

Meeting time: **09:05 - 11:58**

This meeting can be viewed on Senedd TV at:

http://www.senedd.tv/archiveplayer.jsf?v=en_200000_16_01_2013&t=0&l=en

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Concise Minutes:

Assembly Members:

Mark Drakeford (Chair)
Gwyn R Price (In place of Mick Antoniw)
Rebecca Evans
William Graham
Elin Jones
Darren Millar
Lynne Neagle

Witnesses:

Nick Starling, Association of British Insurers
Dominic Clayden, Association of British Insurers
Fay Glasspool, Association of British Insurers
Simon Cradick, Forum of Insurance Lawyers
Michael Imperato, Association of Personal Injury Lawyers (APIL Wales)
Sam Ellis, Association of Personal Injury Lawyers (APIL Wales)
Simon Jones, Marie Curie Hospice

Committee Staff:

Steve George (Clerk)
Olga Lewis (Deputy Clerk)
Fay Buckle (Clerk)
Claire Griffiths (Deputy Clerk)
Gwyn Griffiths (Legal Advisor)
Robin Wilkinson (Researcher)
Stephen Boyce (Researcher)

1. Introductions, apologies and substitutions

1.1 Apologies were received from Kirsty Williams and Lindsay Whittle. Gwyn R Price substituted for Mick Antoniw and Jenny Rathbone substituted for Vaughan Gething.

2. Recovery of Medical Costs for Asbestos Diseases (Wales) Bill: Stage 1 – Evidence Session 4

2.1 The Committee took evidence from the representatives of the Association for British Insurers.

2.2 The Chair asked that a copy of the letter that he had received from the Law Commission should be made available to the witnesses.

2.3 The Committee agreed that it would be helpful to have a paper from the Research Service on the 2002 Department of Health Consultation to which the witnesses had referred.

3. Recovery of Medical Costs for Asbestos Diseases (Wales) Bill: Stage 1 – Evidence Session 5

3.1 The Committee took evidence from the representatives of the Forum of Insurance lawyers

4. Recovery of Medical Costs for Asbestos Diseases (Wales) Bill: Stage 1 – Evidence Session 6

4.1 The Committee took evidence from the representatives of the Association of Personal Injury Lawyers (APIL Wales).

5. Recovery of Medical Costs for Asbestos Diseases (Wales) Bill: Stage 1 – Evidence Session 7

5.1 The Committee took evidence from the representatives of Marie Curie Cancer Care.

6. Papers to note

6.1 The Committee approved the minutes of the meeting held on 10 January 2013.

7. Motion under Standing Order 17.42 to resolve to exclude the public from the meeting for the following business:

7.1 The Committee resolved, in accordance with Standing Order 17.42(ix), to meet in private for item 8.

8. Social Services and Wellbeing (Wales) Bill: Consideration of Expert Advisers

8.1 Members requested additional time to consider the policy candidates but agreed that a formal approach could be made to their preferred legal candidate.

Health and Social Care Committee

Meeting Venue: **Committee Room 1 – Senedd**

Meeting date: **Thursday, 24 January 2013**

Meeting time: **09:01 – 15:40**

This meeting can be viewed on Senedd TV at:

http://www.senedd.tv/archiveplayer.jsf?v=en_800000_24_01_2013&t=0&l=en
http://www.senedd.tv/archiveplayer.jsf?v=en_200000_24_01_2013&t=0&l=en

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Concise Minutes:

Assembly Members:

Mark Drakeford (Chair)
Mick Antoniw
Gwyn R Price
Rebecca Evans
Vaughan Gething
Jenny Rathbone
William Graham
Elin Jones
Lynne Neagle
Lindsay Whittle
Kirsty Williams

Witnesses:

Lesley Griffiths, Minister for Health and Social Services
Mark Osland, Deputy Director of Finance, Health and Social Services, Welsh Government
Fiona Davies, Welsh Government
Dr Rachel Iredale, Tenovus
Julia Yandle, Tenovus
Ceri Phillips, Cymdeithas yr Iaith
Glyn Jones, NHS Confederation
Paul Davies, Welsh Institute for Health and Social Care
Grant Duncan, Welsh Government
Sarah Wakeling, Welsh Government
Pat Vernon, Welsh Government
Roy Thomas, Kidney Wales Foundation
Sally Johnson, NHS Blood and Transplant

Committee Staff:

Steve George (Clerk)
Olga Lewis (Deputy Clerk)

Sarah Beasley (Clerk)
Sarah Sargent (Deputy Clerk)
Joanest Jackson (Legal Advisor)
Gwyn Griffiths (Legal Advisor)
Victoria Paris (Researcher)
Robin Wilkinson (Researcher)

1. Introductions, apologies and substitutions

1.1 Apologies were received from Darren Millar. Gwyn Price substituted for Mick Antoniwi for Items 1–6. Jenny Rathbone substituted for Vaughan Gething for Items 1–6.

2. Recovery of Medical Costs for Asbestos Diseases (Wales) Bill: Stage 1 – Evidence Session 8

2.1 The Committee took evidence from the Minister for Health and Social Services, Welsh Government. The Minister was accompanied by her officials.

3. Recovery of Medical Costs for Asbestos Diseases (Wales) Bill: Stage 1 – Evidence Session 9

3.1 The Committee took evidence from the representatives of Tenovus, Professor Ceri Phillips from Swansea Centre for Health Economics and Mr Glyn Jones, who represented Aneurin Bevan Health Board.

4. Motion under Standing Order 17.42 to resolve to exclude the public from the meeting for the following business:

4.1 The Committee resolved, in accordance with Standing Order 17.42(ix), to meet in private for item 5.

5. Recovery of Medical Costs for Asbestos Diseases (Wales) Bill: Consideration of Member in Charge's evidence

5.1 The Committee considered this item in private session.

6. Recovery of Medical Costs for Asbestos Diseases (Wales) Bill: Stage 1 – Evidence Session 10

6.1 The Committee took evidence from the Member in Charge of the Bill, Mick Antoniwi AM, Vaughan Gething AM, Mr Paul Davies and Mrs Joanest Jackson.

7. Human Transplantation (Wales) Bill: Stage 1 – Evidence session 1

7.1 The Committee heard evidence from Lesley Griffiths AM, the Minister for Health and Social Services; Dr Grant Duncan, Deputy Director Medical Directorate, Welsh Government; Pat Vernon, Policy Lead for the Bill; and Sarah Wakeling, Legal Services, Welsh Government.

8. Human Transplantation (Wales) Bill: Stage 1 – Evidence session 2

8.1 The Committee heard evidence from Roy Thomas, Executive Chairman of Kidney Wales Foundation.

9. Human Transplantation (Wales) Bill: Stage 1 – Evidence session 3

9.1 The Committee heard evidence from Sally Johnson, Director of Organ Donation and Transplantation, NHS Blood and Transplant.

10. Papers to note

10.1 Letter from the Chief Statistician – Content and timing of official statistics on health

10a.1 The Committee noted the letter.

10.2 Letter from the Minister for Health and Social Services – Actions arising from 5 December meeting

10b.1 The Committee noted the letter.

TRANSCRIPT

View the [meeting transcript](#).

Agenda Item 7

Draft Human Transplantation (Wales) Bill

This paper is offered as a guide to issues raised by the Bill (& its memorandum of explanation) ahead of the meeting at the National Assembly on February 7.

The Welsh Assembly Government has bent over backwards to consult on these proposals: with its specialist advisory groups, its public consultation and its active programme of local opinion finding. (The latter was well intentioned, but the numbers too small to be reliable. As its report makes clear some of the findings were contradictory. Nevertheless, it was a good effort).

On the central issue, let me reiterate that I strongly support the intention of the Bill. Transplants save lives; transplants enhance lives. They are also cost effective: transplantation is cheaper than dialysis, for example.

The draft Bill and its explanatory memorandum are, in the main, well written and understandable. The term ‘presumed consent’ has, mercifully, been expunged. What now appears is ‘deemed consent’. I interpret this to mean that the person from whom organs will be removed has not consented but will be treated as if they have. (It might be helpful to acknowledge that in the Memorandum). That is now correct; ‘presumed consent’ (despite its previous use in the Health, Well Being and Local Government Report) was wrong. Consent, to repeat, can never be presumed: that is definitional of consent. Similarly the term ‘donation’ or ‘donor’ implies giving. Giving is voluntary. If there is no knowledge that someone wanted to give, then it is not a gift. It is something removed, not donated. That does not make it morally objectionable, merely inappropriate and – in an extreme view – coercive use of language.

The chief problem with this Bill remains its underlying justification. Organ donation has risen by about 50% since the UK Organ Donation Task Force Report. In Wales 37% are now on the register, an achievement of which Wales should be proud. It is not “only” 37%. There is nothing in the Explanatory Memorandum to the Bill to suggest that a further significant improvement can be achieved by this legislation. We know that Spain, in particular, has the best record in Europe for transplants and we also know that it is not the result of its opt out system.

Para 13 of the Explanatory Memorandum states that “nothing could be further from the truth” that organs will be taken compulsorily or automatically. If there are no family members available to act as advocates against, then the organs will be taken. I have no moral difficulty with that: but I also don’t think it is ‘nothing further from the truth’. It strikes me as pretty close to the truth! The problem with soft opt out is that it is very close to what currently happens when consulting the potential source patient’s family. Insofar as the possible patient’s wishes are downgraded, it is not difficult to understand how some will construe this as the person’s body becoming the property of government: even though it doesn’t. It is legitimate for the state to act on the basis of the best interests of society while protecting minority beliefs. Given the balance of benefit, perhaps the memorandum should make the case for the Bill with greater moral force about the contrast between organs transforming lives, on the one hand; and organs being eaten by worms or burned to ashes on the other. Failure to maximise benefit when the personal cost (i.e. by the source patient) is so minimal (actually nil, as they are then dead) and the potential for good so high makes the moral calculus, in my view, clear.

The problems with the Bill are the hazards it creates for damaging the present programme of transplantation. That damage will be contingent on certain practicalities and how they are handled. A single mishandled opportunity in the hands of a critical media could create havoc with donation numbers; a vociferous opposition could prime the public in a negative manner if practical issues are not addressed. Among these are the way the modified Register is operated. There is a substantial potential for confusion in the single opt in/opt out register. 'Opting in' could fall, while 'opting out' would take us little further on than where matters stand at present. The practicalities of constant reminders of the system will be challenging. It will require different materials compared to England and Scotland: for example, the invitation on Boots Advantage Card membership may require amending. In principle this represents no problem, but practice may be more difficult.

The biggest single problem with the Bill is the lack of data to predict (or even make probable) its success. The Bill has been introduced in the face of two expert inquiries: one UK wide which was unanimous despite starting with divided opinions; and one in Wales with a 2:1 majority against. It is nowhere adequately explained why these two expert groups got it wrong. After all, the Task Force's other recommendations have surely been responsible for rising rates of donation across the UK. The track record of the Task Force has been good so far on the other issues.

Given the manifesto commitment and the advanced stage of planning, this point may be considered a battle lost for opponents of the Bill; and I would tend to agree with that. However it does emphasise the importance of agreeing what would constitute success. Politicians do not have a high place in public esteem. (I personally think that is overall rather unfair, but that is beside the point). The risk is that if donation continues to rise at the same rate as it is currently rising, there will be a political incentive to now claim that it results from the Bill, when it would have happened anyway. Whether we like it or not, Wales is a pilot project for the rest of the UK. If it can be clearly demonstrated that the Bill really has made a difference, then England and Scotland and Northern Ireland will follow suit, to the great benefit of thousands of patients. If the numbers transplanted falls then the reverse applies. It is therefore critical that what constitutes success is set out in advance and not the subject of argument afterwards. I appreciate the difficulties of creating 'counterfactuals' as discussed at paragraph 93 and the section on Regulatory Impact Assessment is short on detail. It would be helpful to discuss how this might be improved.

This paper emphasises issues previously articulated in the paper submitted by the Royal College of Physicians of London. I declare an interest as the main contributor to that paper and continue to hold the views in it. You may wish to consider queries and opinions arising from it alongside this briefer submission.

John Saunders

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Chair, Donation Committee ABHB (the views above do not represent the views of ABHB)