

Health and Social Care Committee

Meeting Venue:
Committee Room 1 – Senedd

Meeting date:
30 January 2013

Meeting time:
09:00

Cynulliad
Cenedlaethol
Cymru

National
Assembly for
Wales



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Committee Clerk

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Agenda

1. Introductions, apologies and substitutions

2. Social Services and Well-being (Wales) Bill: Approach to scrutiny

(09:00 – 09:15) (Pages 1 – 23)

HSC(4)-04-13 paper 1

3. Human Transplantation (Wales) Bill: Stage 1 – Evidence session 4

(09:15 – 10:00) (Pages 24 – 27)

Clinical Lead for Organ Donation, Cwm Taf Health Board

Dr Dariusz Tetla, Clinical Lead for Organ Donation, Cwm Taf Health Board

Professor Vivienne Harpwood, Chair of the Cwm Taf Organ Donation Committee

Academy of Royal Colleges Wales

Dr Peter Matthews

4. Human Transplantation (Wales) Bill: Stage 1 – Evidence session 5

(10:00 – 10:45) (Pages 28 – 44)

Human Tissue Authority

Alan Clamp, Chief Executive

British Transplantation Society

Chris Watson

Break (10:45 – 11:00)

5. Human Transplantation (Wales) Bill: Stage 1 – Evidence session 6 (11:00 – 11:45) (Pages 45 – 53)
UK Donation Ethics Committee

Sir Peter Simpson, Chair of the UK Donor Ethics Committee

Nuffield Council on Bioethics

Dr Tim Lewens

6. Human Transplantation (Wales) Bill: Stage 1 – Evidence session 7 (11:45 – 12:30) (Pages 54 – 55)
Professor Ceri Phillips

7. Papers to note (Page 56)

8. Motion under Standing Order 17.42(ix) to resolve to exclude the public from item 1 of next weeks meeting (7 February 2013) (12.30)
Item 1 (7 February 2013)

Health and Social Committee

HSC(4)–04–13 paper 1

Social Services and Well-being (Wales) Bill – Stage 1 consideration

To: Health and Social Care Committee
From: Legislation Office
Meeting date: 30 January 2013

Purpose

1. To outline the role of the Committee at Stage 1.
2. To invite the Committee to consider and agree the terms of reference and approach to Stage 1 scrutiny of the Social Services and Well-being (Wales) Bill ('the Bill').

Background

3. On 22 January, the Business Committee referred the Bill to the Health and Social Care Committee ('the Committee'), with a reporting deadline of 21 June 2013.
4. On 28 January, Gwenda Thomas AM, Deputy Minister for Children and Social Services, will introduce the Bill and Explanatory Memorandum. She will also make a statement in plenary on 29 January.
5. A background briefing on the Bill has been prepared by the Research Service; this document is provided separately.

Role of the Committee

6. The role of the Committee at Stage 1 is to "consider and report on the general principles of the Bill" (SO 26.10).

7. There are no specific requirements in Standing Orders governing the way in which the Committee carries out this work. On this basis, draft terms of reference are set out in paragraph 9 of this paper, and a suggested approach to scrutiny is set out in paragraphs 10–15.
8. Once the Committee has reported, there will be a Stage 1 debate in plenary. At the end of this debate, the Assembly will be asked to agree the general principles of the Bill. If these are agreed, the Bill progresses to Stage 2, which involves the consideration and disposal of amendments by the Committee (Stage 2 is currently scheduled to take place during September/October 2013).

Draft Terms of Reference

9. In scrutinising the general principles of the Bill at Stage 1, it is suggested that the Committee agrees the following terms of reference:

To consider the general principles of the Bill and the need for legislation that aims to make provision for:

- Consolidated Welsh legislation that simplifies and clarifies duties that would aid the efficient delivery of social services and reduce the time and effort required to understand the current legal framework;
- New legislation that would restate the Welsh Government's commitment to integrated social services for both adults and children and their carers with a Director of Social Services responsible for both. The Bill allows for a Director to be responsible for social services in more than one local authority. Provisions in the Bill aim to promote partnership and closer, more integrated working between local authorities and between local authorities and other bodies, including NHS providers. Joint working provisions in the Bill would facilitate the reform of adoption services;
- The strengthening of national direction and increased consistency of access to and provision of social services across Wales and to introduce and enhanced prevention and early intervention (and well-being) role for

local authorities and their partners to prevent or delay the need for care and support.

- The promotion of the empowerment of service users – enhancing voice and control.

Committee's approach to Stage 1 scrutiny

10. In line with the deadline set by the Business Committee, the Committee will need to complete its scrutiny of the Bill and lay its report no later than 21 June.
11. The reporting deadline allows 16 sitting weeks in which to undertake this work, although it will have to be carried out alongside the Committee's other policy and legislation work. Given the heavy workload of the Committee there are currently 5 evidence sessions scheduled with external witnesses and 2 with the Deputy Minister for Children and Social Services.
12. The Committee has previously agreed the following general approach to scrutiny of legislation at stage 1:—
 - **General call for evidence**
Issue a general call for evidence, which would be notified to the Welsh media and published on the Assembly's website.
 - **Invite written submissions**
Invite written submissions from selected organisations and individuals. A suggested list of consultees is attached at Annex 1.
 - **Oral evidence**
Invite key stakeholders to give oral evidence at future meetings (alongside the consultation exercise). A suggested approach to managing the oral evidence sessions is to 'theme' the 5 scheduled sessions to mirror the main provisions of the Bill. A suggested schedule is attached at Annex 2.
 - **Engagement/Outreach**

Attached at Annex 3 is a proposed outline for engagement and outreach work to support the committee in undertaking its work. Given the deadlines involved, some options are more viable than others.

13. The reporting deadline allows for a 6-week consultation period, from 1 February to 15 March. This will enable written evidence to be considered and used to inform the oral evidence sessions.
14. The evidence gathered, both written and oral, will help inform the Committee's consideration of the Bill and its subsequent report.
15. For information, the Assembly's Standing Orders enable both the Finance Committee and the Constitutional and Legislative Affairs Committees to report on the relevant aspects of Bill.

Action

16. The Committee is invited to agree:
 - the draft terms of reference (as outlined in paragraph 9);
 - its approach to Stage 1 scrutiny (as outlined in paragraphs 10 – 15);
 - to a six-week consultation exercise and the list of consultees (Annex 1);
 - agree the themed approach to scrutiny of the Bill (Annex 2, and
 - note and comment on the proposed engagement and outreach work to support the committee (Annex 3).

Annex 1

Suggested persons/organisations to contact for written evidence:

*Responded to Welsh Government Consultation

Health Boards and NHS Trusts in Wales
Abertawe Bro Morgannwg University Health Board
Aneurin Bevan Health Board
Betsi Cadwaladr University Health Board
Cardiff and Vale University Health Board
Hywel Dda Health Board
Cwm Taf Health Board
Powys Teaching Health Board
Velindre NHS Trust Board
Welsh Ambulance Service NHS Trust
Public Health Wales
Community Health Councils
Board of Community Health Councils in Wales *
Abertawe Bro Morgannwg
Aneurin Bevan CHC (Gwent,Caerphilly,Torfaen,Newport, Mon)
Betsi Cadwaladr CHC (Conwy,Gwynedd,Ynys Mon)
Brecknock and Radnor CHC
Cardiff & The Vale CHC
Cwm Taff CHC
Hywel Dda CHC
Montgomery CHC
Local Government – Chief Executives, ADSS, ADEW
Blaenau Gwent County Borough Council
Bridgend County Borough Council

Caerphilly County Borough Council
Cardiff County Council
Carmarthenshire County Borough Council
Ceredigion County Council
City and County of Swansea
Conwy County Borough Council
Denbighshire County Borough Council
Flintshire County Borough Council
Gwynedd Council
Isle of Anglesey County Council
Merthyr Tydfil County Borough Council
Monmouthshire County Borough Council
Neath Port Talbot County Council
Newport City Council
Pembrokeshire County Council
Powys County Council
Rhondda Cynon Taff County Borough Council
Torfaen County Borough Council
Vale of Glamorgan Council
Wrexham County Borough Council
Welsh Local Government Association *
Safeguarding Children Boards
Blaenau Gwent County Borough Council
Bridgend County Borough Council
Caerphilly County Borough Council
Cardiff County Council
Carmarthenshire County Borough Council

Ceredigion County Council
Denbighshire County Borough Council
Flintshire County Borough Council
Gwynedd Council
Merthyr Tydfil County Borough Council
Torfaen County Borough Council
Neath Port Talbot County Council
Newport City Council
Pembrokeshire County Council
Powys County Council
Rhondda Cynon Taff County Borough Council
City and County of Swansea
Vale of Glamorgan Council
Wrexham County Borough Council
All Wales Youth Offending Team Managers Cymru
Bridgend County Borough Council
Caerphilly County Borough Council
Cardiff County Council
Carmarthenshire County Borough Council
Ceredigion County Council
Denbighshire County Borough Council
Flintshire County Borough Council
Gwynedd Council
Merthyr Tydfil County Borough Council
Monmouthshire County Borough Council
Neath Port Talbot County Council
Newport City Council
Pembrokeshire County Council

Powys County Council
Rhondda Cynon Taff County Borough Council
City and County of Swansea
Vale of Glamorgan Council
Wrexham County Borough Council
Official Agencies
CAFCASS Cymru
Care and Social Services Inspectorate Wales *
The Children's Commissioner for Wales *
Equality and Human Rights Commission
Health and Safety Executive
Healthcare Inspectorate Wales *
Health Protection Agency
Institute of Rural Health
NHS Wales Informatics Service
National Institute for Health and Clinical Excellence
National Leadership and Innovation Agency for Healthcare
The Older People's Commissioner for Wales
Social Care Institute for Excellence *
Social Services Improvement Agency
Professional Bodies
ADEW
ADSS Cymru
Association of Directors of Social Services
British Association of Social Workers Cymru *
National Association of Probation Officers
Royal College of Physicians
The Welsh NHS Confederation

Voluntary Sector
Action on Hearing Loss Cymru
Action for Children
Adoption UK *
Age Cymru – My Home Life Project *
Aids Trust Cymru
All Care
All Wales Forum of Parents and Carers
All Wales People First
Adoption Register UK
Anheddau Cyf
Arthritis Care in Wales
Association for Real Change Wales
Association for Spina Bifida and Hydrocephalus in Wales
Ategi Ltd
Autism Cymru
Black Voluntary Sector Network Wales
Bobath Children’s therapy Centre Wales
British Deaf Association Wales
British Heart Foundation Cymru
British Institute of Learning Disabilities
British Red Cross
Carers Trust Wales
Disability Rights UK
Cerecare Nursing and Domiciliary Services
Chwarae teg
Civil service Pensioners Alliance
CLIC Sargent

Community Practitioners and Health Visitors Association
Community Transport Association
Consumer Focus Wales
Contact the Elderly
Crossroads Caring for Carers
Cruse Bereavement Care Cymru
Cymorth Cymru
Cystic Fibrosis Trust
Daybreak (Wales) Ltd. (no e-mail address/telephone number available)
Dementia UK
Depression Alliance
Disabled Children Matter
Diabetes Cymru
Epilepsy Wales
Gingerbread
GISDA, John Edwards, Office Manager
Grandparents Association
Independent Age
Macmillan Cancer Support
Merched y Wawr
Mothers Union in Wales
Minority Ethnic Women's Network Wales
MDF the Bipolar Organisation Cymru
Mudiad Ysgolion Meithrin
NACRO Cymru
National Autistic Society in Wales
National Childbirth Trust
National Deaf Children's Society Wales

National Federation of Royal Mail and BT Pensioners
National Federation of Women's Institutes
National OAP Association of Wales
National Pensioners' Convention
New Family Social
NIACE Dysgu Cymru
Older People's Advocacy Alliance
One Voice Wales
PACT
Parents Federation
Parkinson's UK Cymru *
Patients Association
Pensioners Forum Wales
Sense Cymru
RNIB Cymru
RNID Cymru
Royal British Legion
Save the Children
SNAP Cymru
Stonewall Cymru
BAAF *
TACT Cymru
The Disability Can Do Organisation
Vision 21 (Cyfle Cymru)
Wales Carers Alliance
Wales Mobility and Driving Assessment Service
Wales Neurological Alliance
Wales Senate of Older People

Wales Carers Workers Network
Wales Council for the Blind
Wales Council for the Deaf
Welsh Reablement Alliance
WRVS *
Housing providers, Independent sector and representative bodies
Association of Retirement Housing Managers
Centre for Housing and Support
St Davids Children Society *
EroSH (Essential Role of Sheltered Housing)
National Care Association
North Wales Care Association
Registered Nursing Home Association
UK Home Care Association
Melin Homes
Abbeyfield Homes
Valleys to Coast Housing
Seren Group
Pennaf Housing Group
Chartered Institute of Housing Cymru
Family Housing Association (Wales)
Academia
Welsh Institute for Health and Social Care (WIHSC)
Bangor University School of Social Sciences
Swansea University Centre for Innovative Ageing
Centre for Social Carework Research
Institute of Medical and Social Care Research – Dementia Services Development

Centre Wales
Cardiff University
Older People & Ageing Research and Development Network (OPAN Cymru)
Bangor Law School
Aberystwyth Law School
Swansea Law School
Glamorgan Law School
Cardiff Law School
Social Services Research Group
Regional Social Care Partnerships
South East Wales
South West Wales
North Wales

Mid Wales
Trade Unions
UNISON
Unite
Wales TUC
Chief Constables of Police Forces
Dyfed Powys
Gwent
North Wales
South Wales
Chief Fire Officers of Fire and Rescue Services in Wales
Mid & West Wales, Richard Smith, Chief Fire Officer
North Wales, Simon A Smith, Chief fire Officer's PA,
South Wales, Huw Jakeway, Chief fire Officer
Other
Wales Cooperative Centre
National Institute for Social Care and Health Research (NISCHR)
Community Pharmacy Wales

Respondents to Welsh Government consultation

Administrative Justice and Tribunals Council
 Advocacy Matters
 After adoption
 Age Alliance Wales
 Age Connects – Age Cymru
 Alzheimers Society
 Barnardos
 Black Association of Women Step Out (BAWSO)
 British Geriatric Society Wales
 British Lung Foundation
 Board of Community Health Councils (CHCs)

BUPA
Care and Repair
Care Co-ordination Network Cymru
Care for the Family
Care Forum Wales
Carers Wales
Cartrefi Cymru
CCW
Chartered Society of Physiotherapy
Children in Wales
Care for the Family
Citizens Advice Cymru
College of Occupational Therapists
Community Housing Cymru
Community Lives Consortium
Contact a Family
Consortium of Voluntary Adoption Agencies
Dignified Revolution
Disability Wales
Diverse Cymru
Domiciliary Care Association Wales
Downs Syndrome Association
FNF Both Parents Matter Cymru
Fostering Network Wales
GOFAL
GRWP Gwalia
Hafal
Hafod Care
Haven Trust
Information Commissioners Office
Joseph Rowntree Foundation
Law Society
Learning Disability Wales
Leonard Cheshire Disability
Linc Care
Lles Cymru/Wellbeing Wales
Mencap Cymru
Mental Health Advocacy Providers
Motor Neurone Disease Association
MS Society
National Aids Trust

National Offender Management Service Cymru
Nationwide Association of Fostering Providers
North Wales Adoption Service
NSPCC
Perthyn, Assistant Director, Christine Rees
Post Adoption Centre
Public Health Wales
Public Services Ombudsman for Wales
Royal College of General Practitioners Wales
Royal College of Nursing
Royal College of Nursing (Wales) Dignified Care Group
Royal College of Paediatrics and Child Health
Royal College of Psychiatrists in Wales
Royal College of speech & language therapists
Royal Pharmaceutical Society
Scope
Stroke Association
Tai Pawb
Tros Gynnal Plant
Tunstall Healthcare
United Welsh Housing Association
Voices from Care
Wales Audit Office
WCVA
Welsh Language Commissioner
Welsh Physiotherapy Leaders Advisory Group
Welsh Refugee Council

Annex 2

Suggested themes for organising scrutiny of the Bill

1. Overarching principles of the Bill:

- Key principles of the Bill
- Core principles of the Bill
- Is the Bill designed to deliver future Social Services
- Promoting user-led and socially-orientated services (social enterprise, user-led, voluntary sector etc.)

2. Access to services by adults, children and carers:

- Well-being duties, preventative services, information and advice
- Assessing adults, children and carers
- Meeting the needs of adults, children and carers, including Direct Payments
- Charging and financial assessment

3. Services for looked after/accommodated/adopted children:

- Looked After Children, review of cases, leaving care
- Accommodated Children, secure accommodation
- Adoption

4. Safeguarding adults and children:

- Adult protection arrangements
- National Independent Safeguarding Board
- Safeguarding and Protection Boards

5. Social services functions:

- Social services functions, Directors of social services
- National outcomes framework and codes
- Collaboration, integration and partnership

- Complaints and representations
- Other – including ordinary residence, recovery of costs etc. central government intervention

Annex 3

Health and Social Care Committee

Social Services and Well-being (Wales) Bill

Stage 1 Scrutiny – Communications Proposal

Introduction

As part of its Stage 1 scrutiny of Bills Committees would normally undertake consultation and engagement work. This would usually consist of a general call for evidence, invite written submissions, gather oral evidence in committee and work with the Assembly's Outreach Team to engage with a section of the general public to gauge views on the Bill.

Given the size and complexity of the Social Services and Well-being (Wales) Bill it is suggested that the committee may wish to consider utilising a wider range of communication and engagement tools to assist in undertaking its Stage 1 scrutiny.

This paper sets out methods of engagement that can be delivered by the Assembly Outreach Team and includes a number of suggestions for consulting with target audiences based on initial consultation with a sample of relevant individuals and organisations.

Once the Committee has considered these options and agreed any methods of engagement that they wish to pursue, the Outreach Team will work with the Legislation Clerks and Research Service to develop a structure for support and delivery.

Suggested Methods of Engagement

Events

Events and visits are an opportunity for the Committee to:

- Promote the inquiry;
- Provide AMs with an opportunity to speak to interested individuals and groups;

A number of groups are set to hold events in the Senedd during Stage 1 scrutiny of the Bill and Members may wish to engage with these. They include:

February

- The Roy Castle Lung Cancer Foundation (4/2/13)
- WGC Homelessness (7/2/13)
- Diverse Cymru (8/2/13)
- Save the Children (19/2/13)
- University of Glamorgan Public Affairs Lecture (19/2/13)
- Rare Disease Day (20/2/13)
- Marie Curie Daffodil Appeal (26/2/13)

March

- International Women's Day (8/3/13)
- Looking into abuse (6/3/13)
- World Social Work Day (20/3/13)
- Cymorth Cymru (21/3/13)

Advisory Group

We are aware that there are a number of external organisations, have shown an interest in actively engaging directly with committee members, with a view to influencing and advising on the committee's stage 1 consideration of the Bill.

As such, through discussions with the committee chair and support from some committee Members, it has been suggested that these organisations form an advisory group, to avoid duplication of engagement whilst also developing partnership working. The Group will benefit from bringing together organisations that would normally engage individually with Assembly Members. The Advisory Group will also be able to co-ordinate specific advice from their various areas of expertise, which comprises of a range of active charities within the social care field.

The Advisory Group will provide advice to Committee Members on key issues arising from the proposed legislation, including identification of questions and issues which might be addressed with individual witnesses to the Health and Social Care Committee at Stage One. The Advisory Group will also help to identify some of the legal implications of the changes in legislation and how these interact with the changes in England and current duties on statutory agencies in Wales.

Visits and Involvement of hard-to-reach Groups

For the purposes of this Bill individual committee members may wish to conduct visits to relevant establishments and/or individuals, within their constituencies. Such visits would be informal, with no record taken of proceedings and can be used for the purpose of gathering evidence from those directly affected by the Bill. For example, service users whose service provision may be changed as a result of the Bill.

Gathering evidence from hard-to-reach groups is always a challenge but the Committee may feel that gathering evidence from these groups may be a priority given the nature of this Bill. Involvement of such groups may best be undertaken through visits, as meeting them in their own surroundings is more productive than formal evidence gathering techniques, which can be intimidating.

Such engagement would normally need to be on a face-to-face basis and any evidence gathered would need careful consideration as to how this might be shared with the wider committee or used to inform the scrutiny process.

Similarly, the Committee may also wish to engage with service deliverers at the point of service delivery, through these means.

Expert advisers

The Committee agreed in principle at its meeting on 5 December 2012 that assistance from the relevant field would be helpful and the option was worth exploring. The Committee agreed that it may be beneficial to consider seeking advice from a number of advisers, each of whom could assist with consideration of particular issues, rather than the appointment of a single expert adviser.

Reporters/rapporteurs

Members are familiar with the use of rapporteur groups and may wish to consider this approach with the Bill. Similarly, members may wish to pursue the use of reporters where a single member of a committee is tasked by the committee to report back on a specific subject. The use of reporters may “lend itself” better to the gathering of information as part of the scrutiny of this Bill due to the sensitivity

of some of the issues that may arise. For example, the Children and Young People Committee gathered information from prospective and adoptive parents in a similar way as part of their inquiry into Adoption. Such an approach generated information that could not otherwise have been gathered through the more formal or traditional methods of engagement.

Speed networking event

Members of the Committee have undertaken speed networking events in the past and have found them to be beneficial. This type of event gives Assembly Members a platform to meet with relevant service representatives and service users, to learn more about the field and who the key stakeholders are. Secondly, they provide the relevant parties with a platform to meet with Assembly Members to discuss issues, priorities and campaigns. We understand that as part of the Advisory Group's introduction to the Committee, they are proposing to hold a speed networking event.

Agenda Item 3

Dariusz Tetla
Clinical Lead Organ Donation
Cwm Taf LHB
Dariusz.tetla@nhs.wales.uk

15 January 2013

Health and Social Committee

Dear Sir

Re: Consultation on The Human Transplantation (Wales) Bill

After its establishment at the beginning of 2010 The Cwm Taf Organ Donation Committee has began its work on organ donation. The main objective of the Committee was to fully comply with the Organ Donation Taskforce's recommendations and to increase the number of organ donations.

The Committee has implemented Organ Donation Policy across the health board.

Strong links between Committee Chair, SNODS, CLOD and their counterparts on regional levels have been established either through individual contacts or regional working group - initially WODIG and later as Regional Collaborative Group.

To increase the awareness of organ donation between staff, an intensive education across the LHB has taken place including meetings with nursing staff and doctors in ITU and Emergency Department, the regular presentation of data from the Potential Donor Audit, and 'Ground Round' presentations for trainees and senior doctors.

While it was commonly accepted that the donor potential for Cwm Taf LHB may be lower than in large hospitals the main objective was to increase referral rates, and to reassure that no potential donors had been missed.

As a result of that tremendous effort some decent increase in referral rates has been recorded over last 3 years. There were 9 donors in Cwm Taf LHB who donated 16 organs in total.

As a person who is actively involved in organ transplantation and donation issues I strongly support every initiative which would lead to an increase in the number of organ donations.

In relation to the Human Transplantation Bill:

Section 2 - Relating to the promotion of transplantation

Introducing this legislation would allow an increase in awareness of the public and also increase consent rates for donation. Several initiatives to promote transplantation have been undertaken on local level in Cwm Taf LHB including presentations to medical staff and medical students. There are also plans to give presentations in schools. It may be worth the Committee

considering whether the promotion of organ donation should become obligatory part of educational programmes.

Section 3-8 Relating to lawful transplantation activities and consent

It's commonly known and accepted that organ donation is particularly difficult area of clinical practice. While introducing 'soft' opt-out system may result in increased number of transplantations, it will certainly impose additional burden on medical practitioners.

The coexistence of two different systems within the UK will require clear identification who is or who is not permanent resident in Wales, especially if no relatives of a deceased person are available.

In relation to subsection (3)(a) (b) of section 3 - it is important to identify valid consent for removal of the tissue, obtained in the country where the relevant material was imported from, and the evidence exists to prove it.

Over last 3 years emphasis has been put on clinical training to increase consent rates for transplantations, therefore it is of particular importance to create legislation which will be transparent and clear, especially concerning valid consent. Otherwise some clinicians may feel discouraged from obtaining consent for donation. Having said that, my personal opinion is that the proposed legislation would not impose many changes in the process of obtaining consent compared with the current opt in system.

Section 9-11 relating to offences

It is recognised that a person is liable for his /her actions, but that a person should also have confidence of being protected by law when acting rightly , without leaving grey areas for different interpretations.

I hope that the new legislation would strengthen the foundation of organ transplantation in Wales, which was established a few years ago after introduction Organ Donation Taskforce recommendations, and it would allow further increase in organ donation activity. It is also equally important for medical professionals to stay reassured that the law protect them if they do right things in the right way.

Yours sincerely,

Dariusz Tetla

Academy of Royal Colleges Wales response to the consultation by the Health and Social Care Committee of the National Assembly for Wales on the Human Transplantation (Wales) Bill

The Academy of Royal Colleges Wales' membership comprises 15 Medical Royal Colleges and Faculties. The Academy aims to provide expert specialist advice to promote quality in healthcare for the benefit of patients in Wales.

Individual Colleges and Faculties have submitted their own responses to the consultation and draft bill. We would like to submit some generic comments based on responses submitted directly by the following organisations:

Faculty of Intensive Care Medicine
Royal College of GPs
Royal College of Paediatrics and Child Health
Royal College of Physicians

Section 2, relating to the promotion of transplantation

We welcome the inclusion of a section in the bill relating to the promotion of transplantation. It is important that the public is fully informed and aware of how the new system of deemed consent would operate and the implications that this may have.

The system of opting out will need to be carefully promoted to the public of Wales as there could be a considerable lack of understanding about how this will affect individuals. Patients whose first language is not English or Welsh will need special consideration as they may not understand the implications. Consideration also needs to be given to patients not registered to practices and those whose religious or cultural beliefs prevent removal of tissue and organs after death.

Section 3, relating to lawful transplantation activities

No specific comments.

Sections 4-8, relating to consent

The problems of tracking patients who move about is recognised in the Explanatory Memorandum. As throughout this Bill, its success depends on how far practical issues like this are addressed, as opposed to matters of basic principle.

Given that young people have higher rates of road accidents and hence the potential to be a source of organs, the residency assessment of students and the issues around their consent is important. A student who has started a course in September, takes up residence in late September or early October, is back home in England for a week mid-term and has a road accident immediately after a month at home in early February, for example, would be difficult to determine under the rules.

We would welcome further clarity with regard to the definition of 'ordinarily resident in Wales for at least six months'. In some cases such as with English students, many may still be registered with a doctor in England and be on the electoral role in England and their residency status unclear.

Sections 9-11, relating to offences

No specific comments.

Sections 12 -20, which make general provision

No specific comments.

2. Any potential barriers to the implementation of these provisions and whether the Bill takes account of them.

No specific comments.

3. Whether there are any unintended consequences arising from the Bill.

Potential changes, with a move to a system of 'opt out', could have a significant impact on intensive care medicine resources. The UK has the lowest number of intensive care beds, and fewest intensive care specialists, per 100K population of any developed Western nation.

If deemed consent increases donation rates, it will certainly increase the number of potential donors being referred to intensive care for pre-emptive support until they meet the criteria for brain death or organ donation. Whilst we accept that the bill is predicated upon the very reasonable desire to increase donation rates, unless the bed pool is increased even a small rise in occupancy could have quite a profound and adverse impact upon the needs of other patient groups.

Organs retrieved from Wales would not be prioritised to Welsh residents and there is unlikely to be a significant reduction in the Welsh waiting list for organ donation. This would need to be clear to the public.

4. The financial implications of the Bill (as set out in Part 2 of the Explanatory Memorandum (the Regulatory Impact Assessment), which estimates the costs and benefits of implementation of the Bill).

We would be concerned about the emphasis on opt out process occurring at registration with a GP and the potential increase in additional work out with general medical service provision. There would likely be a considerable burden on GPs to ensure that the details of individuals were recorded accurately at the time of registration and for individuals to be made aware and to be informed about consent. We welcome the recognition of additional costs (included in RIA Appendix 1 of the Explanatory Memorandum) which relate to training requirements for staff to ensure they are competent to take such consent.

5. The appropriateness of the powers in the Bill for Welsh Ministers to make subordinate legislation (as set out in Part 1, paragraph 90 of the Explanatory Memorandum, which contains a table summarising the powers for Welsh Ministers to make subordinate legislation).

No specific comments.

Introduction

1. The Human Tissue Authority (HTA) welcomes the opportunity to respond to the Health and Social Care Committee's consultation on the Draft Human Transplantation (Wales) Bill (the Bill).
2. As the statutory regulator responsible for the consent provisions within the Human Tissue Act 2004 (HT Act), the HTA is charged with ensuring that appropriate and valid consent is in place when organs and tissue are donated from deceased and living people for the purpose of transplantation.
3. The HT Act covers England, Wales and Northern Ireland and requires consent for a number of activities, including organ donation, to be an active and positive act.
4. There are similar provisions in Scotland under the Human Tissue (Scotland) Act 2006 (HT (Scotland) Act), and while the word "authorisation" is used in place of "consent", there is a requirement that this is a positive act and the principle is the same.
5. This response is in regard to the Welsh Government's proposal to introduce an opt-out system for organ donation in Wales. The essence of the proposal is that, for people who both live and die in Wales and who did not make a decision in life on organ donation, the presumption will be that they wished to donate their organs and tissue after death.
6. The HTA has responded to previous consultations on the introduction of an opt-out system for organ donation. These responses can be found [here](#).

The proposal

7. It is of value to set out the main features of the Welsh Government's proposals in order to place this response in context.
8. The Bill introduces the concepts of deemed and express consent. Express consent is identical to the active consent requirement of the HT Act. It is, in the first instance, the consent of the person themselves in life. If that does not exist, the consent of an appointed representative, and, if there is not a representative, then the consent of a person in a qualifying relationship to the donor.
9. Under the Bill express consent will be required for:
 - a. Living organ donation
 - b. Deceased organ donations from children
 - c. Deceased organ donations from adults who lack the capacity to consent
 - d. Deceased donations from people who live and die in Wales but have not been resident for six months or more
 - e. Deceased organ donations from people who die in Wales but who are not resident in Wales
 - f. Deceased organ donations from Welsh residents who die somewhere else in the UK
10. Under the Bill, when an adult Welsh resident who had the capacity to consent dies in Wales, and had registered either a wish to be considered as an organ donor, or their wish not to be an organ donor, this will be acted upon, if possible.
11. If such a person has not registered either a yes or a no, then their consent will be deemed. This means that the starting point of the conversations which will be held with the potential donor's family and friends is that they wished to donate. At present, when there is no recorded wish the family are approached to ask whether they are aware of the wishes of the deceased.
12. The fact that the family will still be involved in the process under the Welsh Government's proposals means that this key safeguard remains in place. Although the family will not have the right to veto the donation if a recorded yes is in place or consent is deemed, if they are able to provide evidence that would satisfy a reasonable person that the deceased did not wish to be a donor this will be accepted.

13. If a person has recorded a no, their family will be informed of this. If a document signed by the deceased, and which post-dates the recorded decision to opt-out, is presented by the family, then donation might be considered.
14. It should be noted that the current legislation (the HT Act) does not give families a veto over the deceased's recorded wishes. When a person has registered on the Organ Donor Register (ODR), and subsequently dies, the role of the family is to let the Specialist Nurse for Organ Donation (SNOD) know whether they had changed their mind, and to provide the medical and lifestyle information necessary to carry out the risk assessment which is required for a decision to be made on whether donation should go ahead. The existing legislation does not make provision for a family to stop a donation because they do not want it to go ahead.
15. In reality, however, the duty of care the surgical and medical teams have to the family of the deceased means that a donation will not usually proceed without their support. This matter is coming to the fore in discussions on deceased donation rates across the UK. The HTA has engaged and will continue to follow with interest these discussions.
16. The HTA believes that there are areas which require further consideration prior to the implementation of the proposed system. However, the operational process as laid out in the explanatory memorandum does not differ significantly from that which operates at present, in the sense that the register will be consulted and a conversation will then be held with the family.
17. What will change is that there will be a new register which will record both wishes to donate and wishes not to donate, and that where the deceased had not made a decision in life, their family will be approached on the basis that he/she wished to be a donor.

The role of the HTA

18. As a statutory regulator, it is not the role of the HTA to either support or object to the proposals of the Welsh Government, which is constituted of the elected representatives of the Welsh people.
19. It is the role of the HTA to provide advice and guidance as required, and this document seeks to provide a detailed response to the areas highlighted in the Committee's letter of 6 December 2012 and other issues for consideration by the Committee. This advice and guidance is based on the experience the HTA has gained since it was established in 2005, and on the provisions of the HT Act as it currently stands.
20. The HTA notes the ethical discussions on the Welsh Government's proposals. However, as a statutory regulator it is outside the remit of the HTA itself to participate directly in such discussions.

Response to terms of reference of the inquiry

21. In its letter of 6 December 2012 the Committee outlined the terms of reference for the inquiry and the HTA has addressed those within its remit below.

The individual provisions set out in the Bill:

Section 2, relating to the promotion of transplantation

22. The HTA has no comments in regard to section 2 of the Bill.

Section 3, relating to lawful transplantation activities

Licensing

23. Under the HT Act a licence is required for two of the activities listed in section 3. These both relate to storage and are included at s.3(2)(a) and (c) of the Bill.

24. The HT Act requires consent (as laid out in section one of the HT Act) for each of these storage activities and as such a licensed establishment must demonstrate that consent is in place as part of the HTA's licensing requirements.

25. Under the Quality and Safety of Organs Intended for Transplantation Regulations 2012 a licence is required for the removal or implantation of an organ. A licence granted by the HTA under these Regulations also requires that HT Act consent is in place.

26. The Welsh Government and the Department of Health will need to ensure that between the three pieces of legislation the licensing requirements for these activities are unaffected by the move to deemed consent in Wales.

Relevant material

27. There is value in noting that section 3 of the Bill refers to "relevant material" rather than just organs. Relevant material is defined at section 16 of the Bill and means "material, other than gametes, which consists of or includes human cells". Relevant material does not include "embryos outside the human body" or "hair and nails from the body of a living person".

28. At present the Welsh Government's plans in regard to deemed consent only address solid organs. However, the Bill provides scope for the transplantation of any relevant material to be lawful with deemed consent. This means that there would be no need for the legislative process to be undertaken to introduce deemed consent to the transplantation of other relevant material.

Import and export

29. Under section 41 of the HT Act the following definitions for import and export are provided:

- a. "Import" means import into England, Wales or Northern Ireland from a place outside England, Wales or Northern Ireland.
- b. "Export" means export from England, Wales or Northern Ireland to a place outside England, Wales or Northern Ireland.

30. Section 3 of the Bill suggests that it is the intention of the Welsh Government that the definitions at section 41 of the HT Act will no longer remain, and in fact, relevant material of the kind mentioned in s.3(2)(c) or (d) will be considered imported if it originates from any jurisdiction outside Wales.

31. If this is the intention, it will be of vital importance for the Welsh Government and NHS Blood and Transplant (NHSBT) to work together to remedy any impact this would have on the allocation and use of deceased donor organs across the UK.

32. Amendments may be required to the HT Act to ensure consistency between this and the Welsh legislation.

33. It will also be important that there is clear and timely communication that the consent requirements of the HT Act in regard to removal of material for the purpose of transplantation remain in place in England and Northern Ireland, and likewise for the HT (Scotland) Act in Scotland.

Section 4-8, relating to consent

Registration of wishes

34. The HTA notes the information provided in the Explanatory Memorandum and Privacy Impact Assessment on the proposed system by which Welsh residents will be able to register their wishes.

35. The HTA further notes that specifying such a system in primary legislation would restrict any changes or amendments that are required to the system in the future. However, without firm assurances as to the system which will be introduced to allow Welsh residents to register their wishes. It is difficult to assess how the process of establishing or seeking consent will differ from that which currently exists.
36. Establishing whether consent is in place and seeking of consent are complex matters and involve communication with people in a period of high emotion. It will be key that any move to a system of deemed consent does not add further complexity and that everyone involved in the process, including clinicians and the family, are informed fully of their role and responsibilities.
37. The HTA believes that the Welsh Government's proposal of a register which allows Welsh residents to both opt-in and opt-out of organ donation is fundamental to guarantee that the wishes of the deceased in life remain paramount. This must be both easy to access and readily available.
38. Such a register would allow the HTA to have greater confidence when drafting a Code of Practice including guidance on deemed consent in Wales, as the practical issues could be clearly addressed and advice provided on what steps should be taken in given circumstances.
39. The absence of such a register could, in the view of the HTA, increase confusion and uncertainty on the proposed system, and could lead to the provision of advice and guidance by any organisation (including the HTA) being unclear and unhelpful.

Living organ donation

40. Under the provisions of the Bill, consent for living organ donation remains "express", in that it is the consent of the individual. In practice it is difficult to imagine when consent to living organ donation could ever be anything other than express, although it should be noted that provision is made in both the Regulations¹ supporting the HT Act and the Bill for living donors who are children or adults who lack the capacity to consent.
41. It is unclear to the HTA why living organ donation is included in the Bill, and on the face of it this inclusion adds complexity and confusion to no identifiable end.

¹ <http://www.legislation.gov.uk/ukxi/2006/1659/contents/made>

Section 9-11, relating to offences

42. Under section 11, consideration should be given to being specific as to who should make a referral to the Director of Public Prosecutions.
43. From the HTA's experience there is merit in policies and procedures being in place from an early stage in order that all involved understand their responsibilities when an offence may have been committed. The Welsh Government may choose not to include this level of detail in the primary legislation; however, it should be available in good time for the proposed 2015 launch date.

Sections 12-20, which make general provision

44. Section 15(6)(b) of the Bill reads "after subsection (6) insert -", the HTA believes this should read "after subsection (5) insert-".

Any potential barriers to the implementation of these provisions and whether the Bills takes account of them

45. Once it becomes law, the Bill will place a number of explicit and implied duties on the Human Tissue Authority. In addition to the requirement to produce a Code of Practice, the HTA is also placed under a duty to superintend the Act. We understand this to mean the provision of advice and guidance on how the legislation should be interpreted.
46. While the HTA has not yet had the opportunity to undertake a full analysis of the impact of the Bill, an initial assessment has identified a number of possible risks to the implementation of the provisions from a regulatory perspective. These relate to our role in advising on the practical circumstances under which consent can be deemed.
47. The HTA currently provides advice on the conditions which need to be fulfilled for consent to be valid. One of these conditions, that consent should be active, will be removed, under certain circumstances, in Wales as a result of the Bill.
48. A further condition is that consent should be informed. It appears to us that for deemed consent to have legitimacy; people affected by it must clearly understand the circumstances under which their consent will be deemed. The explanatory memorandum sets out the communication activity that will support the policy and we provide more detailed views on this in paragraphs 63 to 69. It is the Authority's view that widespread understanding among

people living in Wales, over time, is a pre-requisite to being able to advise on specific circumstances under which consent can be deemed. By extension, any reduction in this understanding may limit our ability to provide such advice.

49. Considering the specific provisions of the Bill, section 4 sets out consent provisions for adults. It states that consent can be deemed where express consent is not present. One of the tests for express consent is “the person has died, and a decision of the person to consent or not to consent to the activity was in force immediately before his or her death”.
50. The explanatory memoranda make clear that the intention is to have a register in Wales which records wishes to opt-in or opt-out. While we believe this is necessary, it will not necessarily be sufficient as a basis for establishing the wishes of the individual in life. That is to say that the register will not, in law, be the sole mechanism by which wishes could be registered. A person could opt-out orally or in writing in a variety of ways. For example, registering a desire to opt-out in a will appears to us to be legitimate. Alternatively, if the family said that the deceased had orally expressed the desire not to donate, this also seems to us legitimate.
51. While express consent to donate might not be identified under the current system (resulting in no donation going ahead), the consequences of failing to identify an express wish not to donate under a system of deemed consent (and the donation proceeding) seem to be of a different magnitude ethically and legally. As a result we would expect to take a range of stakeholder views on the appropriate checks to undertake in order to reflect these in a Code of Practice.
52. While our experience (in partnership with NHS Blood and Transplant) will allow us to develop a Code of Practice, a system so designed may pose a number of operational challenges. We are working with officials in Wales and colleagues in NHSBT to address these issues.

Whether there are any unintended consequences arising from the Bill

53. The HTA has sought to address potential unintended consequences in relation to the sections of the Bill above.
54. In particular, please note paragraphs 23 to 26 above on licensing.
55. More generally, the HTA would further advise that agreed review periods are built into the post-launch programme to allow an assessment of the impact of

the legislation. If the impact is a drop in the number of organs being donated, steps should be taken rapidly to understand the root causes.

56. Negative coverage of deemed consent in Wales could lead to mistrust in other parts of the UK, and it will be vital that this change does not adversely impact organ donation.

The financial implications of the Bill (as set out in Part 2 of the Explanatory Memorandum (the Regulatory Impact assessment), which estimates the costs and benefits of the implementation of the Bill)

57. The table of fixed costs associated with the adoption of the opt-out system on page 45 of the Explanatory Memorandum details that spending on communications will fall in the period 2017-22 to £50k per annum, from a high of £1.453m in 2015-16.
58. The HTA believes that communication will be vital in ensuring the legitimacy of a system of deemed consent, in the sense that without it Welsh residents will not know what action they are required to take in order not have their consent deemed, and would caution that £50k per annum appears to be a low spend for such a vital issue.
59. As noted in previous HTA response documents on this matter, a new group of people will be impacted by the system year-on-year and while steps should have been taken during the implementation and launch phases to raise general awareness, campaigns will be required every year. It is true that in order to maintain the legitimacy of a system of deemed consent there will need to be a continuous communication programme, so those that have made a decision in the past are able to revisit it if they wish.
60. The HTA also questions whether an overall communications spend of £2.9m over ten years is adequate for such a significant legislative and operational change on a sensitive and complex issue.

The appropriateness of the powers in the Bill for Welsh Ministers to make subordinate legislation (as set out in part 1, paragraph 90 of the Explanatory Memorandum, which contains a table summarising the powers for Welsh Ministers to make subordinate legislation)

61. The HTA is not in a position to comment on the appropriateness of the powers in the Bill for Welsh Ministers to make subordinate legislation.

Areas for further consideration

62. The HTA would highlight the following three areas as those which require further consideration and development, and which will be key to the effective implementation and operation of the proposed system.

Communications

63. The commitment made in the Explanatory Memorandum to an effective and sustained communications campaign is noted by the HTA. Communication will be vital in ensuring that every person living in Wales and the bordering counties is aware of the proposed system and how it will affect them. In order for the individual's decision to remain paramount they must be aware of the action they are required to take, if any, to make their views known.
64. Communication with all Welsh residents and those living in the border counties will be important, and attention should be given specifically to those groups who are regarded as being hard to reach. These include those people whose first language is not English or Welsh, and also those living in deprived areas.
65. It will be important to develop a communications plan which ensures people who move to Wales are made aware of the system soon after they become resident, in order to allow them sufficient time to make a decision and, if necessary, record their wishes.
66. The HTA considers that the planned communication with every Welsh resident six months prior to their eighteenth birthday will be important to ensure that there is time for these young people to make an active decision prior to deemed consent applying to them.
67. Any risk of a particular group or groups of Welsh residents being left behind on this matter due to poor communication must be actively addressed by the Welsh Government. Without an effective, comprehensive, targeted and continued communications campaign the proposed system cannot be said to hold the decision of the individual in life as a core principle. Indeed, without proper communication an individual may not be in receipt of the information they require to know what their silence on the matter of organ donation after their death will be considered to mean.

68. In previous responses to the Welsh Government's consultations on an opt-out system for organ donation, the HTA has stressed the importance of a continuous communications campaign. Such a campaign will be critical in ensuring that every Welsh resident remains aware of whether or not the system affects them, and what action they need to take. If the focus on this continuous communications campaign is lost, then there is a significant risk that people will not be properly informed, leading to the whole system being undermined.

69. The HTA intends to continue to work with the Welsh Government to provide input on the communications activity for the proposed system.

Cross-border issues

70. The HTA believes that there is still work to be done on the cross-border issues which arise from the proposed system.

71. The introduction of a register for Welsh residents which records both wishes to donate, and wishes not to donate, would mean that there would be two different registers operating across the UK. In Wales it is envisaged that an individual will be able to record a yes to all organs, a yes to some organs, or an outright no. In the rest of the UK an individual will be able to record a yes to all organs or a yes to some organs. They will not be able to register a no.

72. Operationally this poses challenges as, under the HT Act, it is the wishes of the individual immediately before they died which are held as primary. Therefore if these wishes are recorded on the Welsh register they should be acted on, no matter where the individual dies. This means that, for Welsh residents who die outside Wales, the SNOD will be required to check any Welsh register which exists and act on the recorded wishes, if there are any. In fact, it would be prudent that any Welsh register is checked for every donor, as it may not be clear if they had ever been resident in Wales. By checking both registers the risk that the "wrong" information is relied upon is limited. Therefore, all SNODs must have access to any Welsh register and the Organ Donor Register and be in a position to easily establish whether a person is on either or both registers, and which record is most recent. This information will need to be quickly ascertained, most often in the middle of the night, and its accuracy must be guaranteed.

73. If individuals are able to record their wishes on the new Welsh register prior to implementation of the opt-out system, then this recording will in effect form the

last recorded wishes of the individual. It is vital that these are made available to SNODS in order to ensure compliance with the HT Act.

Post-implementation review

74. The consultation document commits to a thorough and on-going post implementation review and the HTA suggests that this seeks to highlight both successes and challenges. The HTA notes that both the Scottish Government and Northern Ireland Assembly² have expressed interest in the Welsh Government's proposals, and as such the post implementation review may form part of the basis of policy decisions in other parts of the UK. This unique opportunity to share the experience of one country of the UK with others should not be lost, and investigation of the true outcomes for all involved from donor families, to recipients and clinical staff will be key to the wider understanding of how such a system operates.

² <http://www.eveningtimes.co.uk/news/bid-to-change-opt-out-laws-a-step-closer-112363n.19888806>
and <http://www.bbc.co.uk/news/uk-northern-ireland-17089597>

Summary

75. Since the Welsh Government announced their intention to introduce a system of deemed consent for organ and tissue donation in Wales, the HTA has been involved, to a varying degree, in the development of the Welsh Government's proposals which have resulted in the Bill which is the focus of this consultation.
76. The HTA is aware of the wide-range of views which exist on this matter, and as a statutory regulator has sought to provide advice and guidance on matters within its remit and on those areas in which the organisation has gained experience during the past eight years.
77. As detailed above, there are parts of the Bill which the HTA believes require further consideration and exploration.
78. However, it is those areas which are not specified in the Bill, for example the introduction of a Welsh register of people's wishes, the communications strategy and post-implementation review where assurances are needed to give confidence to all involved in the proposal.

Response of the British Transplantation Society

Thank you for asking the British Transplantation Society (BTS) to contribute to contribute to the consultation on the Human Transplantation (Wales) Bill.

1. Individual Provisions set out in the Bill

(a). Section 2, the Promotion of transplantation.

The BTS is delighted to see the inclusion of a section mandating the Welsh Ministers to promote transplantation, provide information and increase awareness about transplantation, and inform the public of the circumstances in which consent will be deemed to have been given. Whether or not one supports “Opting out”, there is no doubt that increased public awareness is vitally important as is government support for transplantation. There is a similar requirement in the Human Tissue (Scotland) Act 2006 to “promote, support and develop programmes of transplantation” as well as to “promote information and awareness about the donation for transplantation of parts of a human body”, and the public awareness campaigns in Scotland have resulted in high rates of registration on the Organ Donor Register and a higher rate of consent to organ donation.

This section of the Welsh Bill and Scottish Act is sadly missing from the Human Tissue Act (2004) that currently applies to the rest of the UK.

(b) Section 3, relating to lawful transplantation activities,

The paragraph relating to storing the deceased person presumably relates to tissue and corneal donation. This seems reasonable. As it reads, the bill might support the removal of organs and tissues for transplantation with “deemed” consent, and these would include the more unusual and emotive forms of transplantation such as hand/arm and face transplants.

(c) Sections 4-8, relating to consent,

Section 4 paragraphs 1 to 3 are not contentious. Paragraph 4 essentially says that the Welsh system will be a soft opt-out, where relatives may oppose organ donation. If opting out legislation is to be introduced then such “soft” opt-out is the type that is favoured by the transplantation profession in the UK.

Section 5 (Consent: excepted adults) is important. In order to ensure a new resident to Wales becomes aware of the legislation within his/her first six months of residence it will be important to continue a programme of public awareness of the legislation at intervals no less than 6 months. The absence of such an undertaking would be a significant cause for concern.

(d) Sections 9-11, relating to offences,

No comments on this section

(e) Sections 12-20, which make general provision.

Section 12a states that it is “lawful (a) to take steps for the purpose of preserving the part for transplantation”. As transplantation advances, all opportunities to recover transplantable organs are being explored. One such relates to potential donors being admitted to an emergency department either dead or in the process of attempted cardiopulmonary resuscitation that then fails. In order to *optimally* preserve organs for transplantation it may be

necessary to administer drugs to the potential donor while maintaining an artificial circulation by cardiac massage, or establishing an extracorporeal circulation of blood to perfuse the organs. Such is the practice in parts of Spain and is also the subject of a pilot in Scotland. The wording of this section would seem to support such interventions in Wales, which go beyond the “minimal steps” permissible under the Human Tissue Act (2004). However the Bill then goes on to say that none of these steps to preserve organs can proceed without prior approval from a coroner (whose jurisdiction will apply to cases of sudden death such as those brought to the emergency department). A requirement for *a priori* approval of a coroner before undertaking “steps for the purpose of preserving the part for transplantation” would effectively prevent such steps from being undertaken in the timely manner that would be required were such donation practices to be explored in Wales.

2. Barriers to implementation

The BTS can see difficulties in ensuring that newcomers who come to live in Wales are provided with the necessary information explained deemed consent. This is not so much a barrier, but a challenge to implementation of the Bill.

3. Unintended consequences of the Bill

Adverse publicity is the major concern of the BTS. If a family were not present at death, but subsequently come forward to say that the deceased did not agree to donation, and that his wishes had been overlooked or that the database recording his wishes (the ODR) was inaccurate (which has happened with the ODR), there would be significant adverse publicity which would damage transplantation not only in Wales, but also the rest of the United Kingdom. The BTS would be reassured to know that contingencies for such an eventuality have been considered and will be in place ahead of such an event.

4. The financial implications of the Bill

The Organ Donor Taskforce report “*The potential impact of an opt-out system for organ donation in the UK*” discussed opt-out legislation in general. One of the considerations during the Taskforce’s deliberations was balancing the high predicted costs of implementation of opting out compared to the lesser costs of a programme of public awareness campaigns, of the sort conducted in Scotland. The predicted costs of introducing opt-out in Wales are, we believe, significantly less than those predicted by the ODTF in their deliberations.

There is no doubt that renal transplantation is a cheaper form of treatment for a patient in renal failure than dialysis, and savings will be made as more patients are removed from the dialysis programmes in Wales. At the moment this is a function of the organ donation activity throughout the United Kingdom, rather than in Wales specifically, since organs are, and will continue to be, exchanged on a National basis to optimise matching and outcomes.

5. The appropriateness of the powers in the Bill for Welsh Ministers

No comment.

Additional comments

It appears that, through this bill, Wales will introduce opt-out legislation, and as such will be the first nation in the UK so to do. The BTS would strongly encourage every effort be made to record the process carefully, detailing the costs and the final outcome, so that the other home nations can learn and assess whether it is something they wish to do. It would be tempting for the government to audit the process itself, but it might be better received externally were some independent assessment be included in the process and we would like to encourage this.

The BTS would like to see provision in new transplant legislation such as this for pharmacological interventions in potential organ donors, particular those potentially donating after circulatory death (DCD). Currently heparin cannot be given pre-mortem to such donors, even if the blood pressure is terminally falling and has fallen below 50mmHg. DCD donors now form a third of all deceased organ donors in the UK and an intervention such as this may make a significant difference to the outcome of transplants. It is permitted in parts of North America.



Ms Sarah Sargent
Dirprwy Glerc / Deputy Clerk
Swyddfa Ddeddfwriaeth / Legislation Office
Cynulliad Cenedlaethol Cymru /
National Assembly for Wales

10, Dallington Street
London EC1V 0DB

Date: 10 January 2013

Dear Ms Sargent,

Consultation on the Human Transplantation (Wales) Bill : written evidence from the UK Donor Ethics Committee (UKDEC)

Thank you for your letter of 6 December 2012, inviting UKDEC to submit written evidence to the inquiry. I am responding as Chairman on behalf of the Committee.

UKDEC was established in 2010 following a recommendation of the Organ Donation Taskforce (ODTF). It is independent, hosted by the Academy of Medical Royal Colleges (with funding from the UK Health Departments). Its purpose is to address the ethical questions that arise in organ donation, in order to remove barriers to effective decision-making in donation and transplantation. It promotes ethical practice and does not seek to increase the number of donations per se. Further information can be found at www.aomrc.org.uk/donations-ethics-committee.html. Membership includes clinicians, ethicists and lay members.

Our submission therefore focuses on the ethical issues relating to the provisions set out in the Bill, including practical issues that have a bearing on good ethical practice. We also have some concerns about potential unintended consequences which are included in the submission.

Individual provisions set out in the Bill

Sections 4-8 : consent

UKDEC sees no fundamental ethical objection to a system of deemed consent or “opt out”, but we do have concerns about the practicalities involved in ensuring consent under such a scheme is valid and will remain so as time moves on. We also have reservations about the impact on the relationship between professionals and donor families, and on the confidence of professionals to explore new and ethically challenging techniques aimed at increasing the number of successful donations. These issues are dealt with in more detail below, where potential barriers and unintended consequences are discussed.

On the specific provisions, we do have concerns about the provisions in relation to adults lacking capacity. The Bill rightly recognises the need to protect people lacking the capacity to understand the notion of opting out. However the proposals for identifying such people do not seem very robust. The criterion of lacking capacity for a “significant period” before death is vague, and the reliance on discussion with families after death might lead to some very subjective assessments

being made. Further work on how these decisions will be made in practice, and what support will be available for professionals and families, would be helpful.

A particular issue arises in the context of donation after circulatory death (DCD), which accounts for nearly 40% of solid organ donations. The decision-making about donation for a DCD donor happens while the donor is still alive, but lacking capacity. Such decisions are therefore covered by the Mental Capacity Act, and in order for donation to proceed it has to be established that activities to facilitate donation are in the patient's best interests. The potential for a move to deemed consent to undermine DCD schemes is discussed further under "unintended consequences", but on a practical and legislative level the Bill needs to be clear on the consent status of a potential DCD donor who may not have opted out, but is still alive and lacking capacity at the time of decision-making about donation.

Potential barriers to implementation

The Bill, and its associated Explanatory memorandum, acknowledges the communications and educational challenges inherent in a switch to a system of deemed consent. From an ethical perspective, clear information about the system and the implications of opting out or not, is clearly a vital component of an ethically acceptable system. Training and support for professionals will also be a key element in ensuring trust in the new system – if the new system is perceived as too complicated this could undermine trust in both professionals and the public.

Others will be better placed to comment on the financial costs, but we do wonder whether the impact on professionals of setting up and maintaining the new system in parallel with a different system in the rest of the UK has been fully recognised. Sections 45 to 54 of the Explanatory Memorandum set out the vision of how the scheme will work in various scenarios, for example should a person have lived in Wales but die elsewhere, or opt-out when they lived in Wales but then move elsewhere. The Bill appears to place a lot of additional burdens on staff across the UK relating to deciding about ordinary residence in Wales, checking different registers etc. Section 52 says "NHS staff across the UK will need to be aware of the law in Wales and the process will need to have a check built in to ask whether the person had ever lived in Wales, and therefore look for any recorded decision made whilst the person lived in Wales". Implementation needs to ensure all staff are fully trained and supported to help families through the process.

A key assumption is that the switch to deemed consent will lead to an increase in donations. Whilst UKDEC recognises the political imperative for introducing deemed consent in Wales, there are doubts about the evidence. Overall systems in different countries vary, and it is not necessarily possible to compare one opt-out system with another. The evidence linking opt-out systems with increased donation is equivocal or at best weakly in favour of opt-out having an effect. In order for confidence in the system to be upheld, those tasked with implementing it will need to be convinced that the time and resources involved could not be better deployed elsewhere.

We note that families will continue to be involved in decision-making under the proposals, albeit on the basis that in the absence of an opt-out, consent will be deemed, unless the family has evidence that the person really did not want to be a donor. Whilst the surveys carried out in Wales show general support for an opt-out scheme, it remains to be seen whether in practice families accept the absence of objection as consent to donation, and what the impact will be on family satisfaction with

the process. We would recommend that implementation be accompanied by well executed social scientific research to provide an evidence base.

Unintended Consequences

The inevitable upward trend in the demand for organs for transplantation means that clinical practice in transplantation needs to constantly evolve and find new and better ways of delivering successful donations. Donation after circulatory death (DCD) is an important potential source of increasing the organs available for transplantation, particularly hearts.

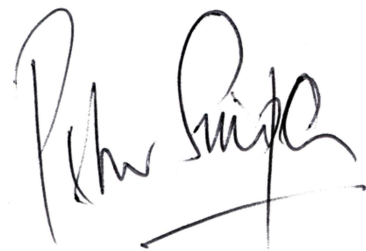
As I mentioned earlier, decisions about DCD donations need to be made whilst the potential donor is still alive. These decisions can be ethically challenging, since there are a range of interventions that might be carried out on a dying patient that will optimise the condition of organs, but have no benefit to the patient other than fulfilling his or her wish to be a donor.

Therefore the justification for intervening, and the balance of benefits and burdens that need to be weighed up in deciding whether an intervention is in the patient's best interests, relies heavily on the strength of evidence that the patient wants to be an organ donor.

UKDEC recognises that there will still be an "opt in" register under the proposals, but we are concerned that a shift towards reliance on the absence of opting out as the basis of consent to donation could shift the delicate balance and undermine professionals' confidence to develop the innovative schemes that have the potential to increase the number of organs for transplantation.

Were this to happen and the unintended consequence limited new opportunities for increasing available organs, this would work against the overall aim of the Bill. We would recommend further work be undertaken on the potential impact on clinical practice in this area.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Peter Simpson', with a stylized, cursive script.

Sir Peter Simpson

Chair, UK Donor Ethics Committee

16 January 2013

Health and Social Care Committee
National Assembly for Wales
Cardiff Bay
CF99 1NA.

Dear Sir / Madam

Health and Social Care Committee Consultation on the Draft Human Transplantation (Wales) Bill

I am pleased to enclose a submission from the Nuffield Council on Bioethics, an independent body that examines and reports on ethical issues in biology and medicine.

In October 2011, the Council published a report, *Human bodies: donation for medicine and research*, which considers the ethical and social issues that arise when people are asked to donate bodily material and sets out an ethical framework to help policy makers consider the acceptability of various ways of encouraging people to donate (see Chapter 5 of the full report).

More information about the inquiry and the resulting report can be found at: www.nuffieldbioethics.org/donation

Our response to the Welsh Government Consultation on Proposals for Legislation on Organ and Tissue Donation on 31 January 2012 is available at:

http://nuffieldbioethics.org/sites/default/files/files/Welsh_opt-out_consultation_Jan_2012.pdf

Our subsequent response to the Welsh Government Consultation on the Draft Human Transplantation (Wales) Bill on 10 September 2012, is available at http://www.nuffieldbioethics.org/sites/default/files/files/Welsh_opt-out_consultation_Jan_2012.pdf

Chair
Professor Jonathan Montgomery

Deputy Chair
Professor Ottoline Leyser CBE FRS

Members
Professor Tom Baldwin
Dr Amanda Burls
Professor Robin Gill
Professor Sian Harding FAHA FESC
Professor Ray Hill FMedSci
Dr Rhona Knight FRCGP
Professor Graeme Laurie FRSE
Dr Tim Lewens
Professor Anneke Lucassen
Professor Michael Moran FBA
Professor Alison Murdoch FRCOG
Dr Bronwyn Parry
Professor Nikolas Rose
Dr Geoff Watts FMedSci
Professor Jonathan Wolff

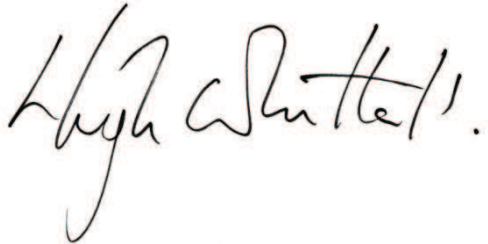
Director
Hugh Whittall

Assistant Directors
Dr Peter Mills
Katharine Wright

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Please do not hesitate to contact me if you would like further information or assistance.

Yours sincerely

A handwritten signature in black ink, reading "Hugh Whittall". The signature is written in a cursive style with a large initial 'H' and a trailing flourish.

Hugh Whittall
Director

Response from the Nuffield Council on Bioethics to the Health and Social Care Committee Consultation on the Draft Human Transplantation (Wales) Bill

With reference to our response to the Welsh Government Consultation on Proposals for Legislation on Organ and Tissue Donation on 31 January 2012 and the Welsh Government Consultation on the Draft Human Transplantation (Wales) Bill on 10 September 2012, we reiterate the following:

Key points:

- Decisions about deceased donation should be based on the known wishes of the donor, so far as these can be discovered.
- We would not oppose on ethical grounds a soft opt-out system, in which families had the opportunity (without pressure) of contributing their knowledge of the person's own views. We do, however, note some practical difficulties in implementation, and some doubts as to the impact of such a change.
- It is important that loss of trust in the system is minimised, for example by ensuring that those seeking family views are not themselves subject to targets that might be seen as leading to pressure on families.
- **If an opt-out system is introduced in Wales this should be accompanied by robust research, both on the role of relatives in determining whether organs may be donated, and on the effect that the legislative change has had on the numbers of organs donated.**
- The possibility of donating material for research use should be routinely raised with the person's family when authorisation for the removal and use of organs or tissue is sought after death.

Introduction

- 1 The Nuffield Council on Bioethics is an independent body that examines and reports on ethical issues raised by new developments in biology and medicine. It is funded jointly by the Nuffield Foundation, the Wellcome Trust and the Medical Research Council.
- 2 In October 2011, the Council published a report, *Human bodies: donation for medicine and research*¹, which considers how far society should go in encouraging people to donate their bodily material. The report was the result of a two-year independent inquiry led by Professor Dame Marilyn Strathern. In coming to its conclusions, the Working Party held an open consultation to which members of the public as well as academics and professionals involved in transplantation services were encouraged to respond. A deliberative workshop was also held with members of the public recruited to represent a cross-section of the UK community.² More information about the inquiry, method of working and resulting report can be found at: www.nuffieldbioethics.org/donation

¹ Nuffield Council on Bioethics (2011). *Human bodies: donation for medicine and research* (London: Nuffield Council on Bioethics). Available at: www.nuffieldbioethics.org/donation

² Opinion Leader (2010) Nuffield Council on Bioethics: human bodies in medicine and research - report of deliberative workshop on ethical issues raised by the donation of bodily material (London: Opinion Leader). Available at: www.nuffieldbioethics.org/donation/donation-externalconsultation

Ethical considerations

- 3 We believe that **decisions about deceased donation should be based on the known wishes of the donor**, so far as these can be discovered. Such information should, ideally, derive from the person's own expression of these wishes before death (see paragraphs 5.57-5.61 of the full report).
- 4 In the absence of a record of the deceased's wishes (including the absence of any evidence of objection), information as to their likely wishes should be sought from those close to the deceased person, who are usually best placed to know the deceased person's wishes, and who themselves, in their bereavement, have a stake in how their deceased relative's body is treated.
- 5 We take this overall view on the basis that there is sufficient evidence that, for many people, the disposal of their bodily material is a matter of significant personal concern, and that to take material without some evidence that this is in accordance with the person's wishes risks treating the person's body as a means to others' ends.
- 6 Clearly not everyone regards their bodily material – during life or during death – in such a way, but the entrenched and opposing views on proposals for an 'opt-out' approach to deceased organ donation highlight the fundamental lack of consensus on this issue within the UK. However, we make a distinction between what is required for valid consent to an intervention during one's lifetime, and what should be required for valid consent in respect of a deceased person's bodily material. In particular, we suggest that the degree of detail required when providing information about the proposed procedure will differ significantly, and that it should be possible for a person to provide legal authority for donation after death on the basis of quite minimal information, if this is sufficient for them to be clear about their own wishes.
- 7 Finally, we emphasise the importance of consent in creating and maintaining trust in health professionals and the health care system as a whole. We note that where 'medical mistrust', or mistrust of the system, is cited as a reason for people to hold back from donating bodily material, this may be associated with concerns about consent: both that the terms of the consent may be abused (for example by using the donated material in a different way from that envisaged in the consent) and that additional material may be taken without explicit consent. This is a factor that must be taken into account when considering any changes to approaches to consent.

Research on effectiveness of opt-out systems

- 8 We are aware of the ongoing discussions in the research literature as to whether increases in organ donation in countries such as Spain that have introduced opt-out legislation can be ascribed to the legislative framework, or whether other systemic factors in the way organ procurement is managed are the main contributing factor to the increase. A systematic review of studies comparing 'before and after' donation rates after legislative change in a number of countries,

published in 2009, concluded that changing to an opt-out system of consent alone was unlikely to explain the variation in organ donation rates between countries, with many other factors identified as relevant. These included both factors affecting the total number of potential donors available (for example rates of motor accidents, the population's age distribution, and the country's definition of death), and factors affecting how many of those potential donors in fact went on to donate (for example the organisation and infrastructure of the transplant system, wealth and investment in health care, and underlying public attitudes and awareness).³

- 9 Another study, published subsequently, concluded by contrast that opt-out systems *are* associated with relatively higher rates of deceased donation – but also with relatively lower rates of living donation.⁴ We are also aware of research modelling the possible effects on organ supply of an opt-out system, based on differing levels of individual and family opt-out.⁵ We note that, while such models demonstrate a potential increase in the number of available organs (and hence lives saved) on the basis of particular assumptions about numbers opting out, such assumptions clearly remain to be tested.

Our recommendations

- 10 In our opinion, **the importance to be attached to the person's own wishes rules out absolutely any consideration of introducing a 'hard' opt-out approach 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.
- 11 However, **we would not oppose on ethical grounds a soft opt-out system**, in which families had the opportunity (without pressure) of contributing their knowledge of the person's own views and, where appropriate, of determining that the person would not have wished to become a donor, or indeed that donation would cause the family significant distress. We do, however, note some practical difficulties.
- 12 First we suggest that **initial assumptions as to the numbers of additional organs that might be obtained in such a way should be modest**, if families do indeed continue to feel genuinely free to express any objections they feel. It does not automatically follow that families who currently refuse consent to the use of their deceased relative's organs would take a different view under such a system. Indeed, if families in such cases felt coerced in any way, then this would potentially render their role meaningless. On the other hand, if the effect of any policy change were to change attitudes so that donation were seen as 'natural' or 'normal', hence increasing the likelihood that families would conclude that donation would be in line with their deceased relative's wishes, this would be

³ Rithalia A, McDaid C, Suekarran S, Myers L, and Sowden A (2009) Impact of presumed consent for organ donation on donation rates: a systematic review BMJ 338.

⁴ Horvat LD, Cuerden MS, Kim SJ et al. (2010) Informing the debate: rates of kidney transplantation in nations with presumed consent Annals of Internal Medicine 153: 64

⁵ Bird SM, and Harris J (2010) Time to move to presumed consent for organ donation BMJ 340: c2188.

ethically unproblematic. Similarly, if families felt relieved from the requirement actively to make the decision, this too might lead to fewer refusals.

- 13 Second, given the strong opposition in some quarters to the notion of any form of opt-out scheme, and the associated concerns that the state (acting through health professionals and the health care system) would be intervening to 'take' organs rather than facilitating their being 'given', there is at least a risk that some degree of trust in the system could be lost. In such circumstances, **it would be particularly important that systems should be designed in such a way as to minimise such loss of trust**, for example by ensuring that those seeking family views are not themselves subject to targets that might be seen as leading to pressure on families.
- 14 As we have already shown, there may be a significant difference between how people think or say they will act in particular theoretical situations, and what they actually do if that situation arises (see paragraph 6.19 of the full report). We are therefore hesitant to rely on research reporting on how people say they would respond to the introduction of a soft opt-out system including all the protections described above. **If an opt-out system is introduced in Wales we recommend that this is accompanied by robust research**, both on the role of relatives in determining whether organs may be donated, and on the effect that the legislative change (as opposed to any confounding factors such as system changes) has had on the numbers of organs donated. Such research would provide a clear evidence base for any proposals for change elsewhere in the UK, or indeed further afield.

Donation of organs and tissue for research

- 15 We note again that current proposals in Wales will apply to the donation of organs and tissues for the purposes of transplantation only, and not include the donation of organs and tissues for other purposes, such as research, display or commercial use.
- 16 We consider that it is crucial that any change in the systems used to obtain consent should take fully into account the implications for the donation of organs and tissue for research purposes. In the context of the current 'opt-in' system to organ and tissue donation, our report recommends that **the possibility of donating material for research use should be routinely raised with the person's family when authorisation for the removal and use of organs or tissue is sought after death**. We also suggested that routine information about the Organ Donor Register should include explicit reference to the potential research uses of organs and tissue, and that potential donors should have the option of authorising such uses in advance.

Agenda Item 6

Human Transplantation (Wales) Bill: personal statement

1. My comments relate primarily to the cost-benefit analysis contained within the Regulatory Impact Assessment.
2. The current supply of organs available for transplant is roughly 41 short of current levels of demand – based on numbers of patients who died while waiting for transplant. It is estimated that the new legislation would result in 15 more donors per year – an increase of 25% and an additional supply of 45 organs available for use in transplantation.
3. The cost-benefit assessment of the soft opt-out system indicated that the predicted increase in donor organs would not incur additional costs in terms of impact on critical care, surgical services including theatre time. However, hospitals are currently operating at capacity levels that allow for no additional procedures given the demands on staff time and the system in general. It is difficult to predict when the potential donors would become available with consequential problems in planning when the relevant procedures would be taking place. It is therefore possible to envisage a situation where it would not be possible to undertake the procedure and the potential donor organ might not materialise and the potential beneficiary not receive the benefits which the policy and the bill is seeking to ensure. Alternatively, the procedure will take place but at the cost of other procedures being cancelled and patients having to face the prospect of additional delays in their waits for surgery.
4. It is not clear whether the policy – if successful - will result in the need for additional staff resources or additional training requirements across Wales.
5. The situation whereby the level of supply of organs exceeds levels of demand in Wales need to be factored into the cost-benefit analysis – the system of charging other systems for transport etc. of donor organs, for example, to increase their respective levels of transplantation warrant consideration.
6. The administration costs of the soft opt-out system need to be considered relative to the current system of organ donation, while the additional costs resulting from an increased number of transplants would be managed by the Health Boards – additional pressure on already stretched resources possibly! However, it has to be recognised that there will be health benefits that emerge as a result of the policy which is the primary goal of the NHS – that is to enhance health status as opposed to ‘making money’!
7. The costs of transplantation, those that are incurred to minimise risk of rejection and on-going treatment costs need to be compared with the costs offset as a result of the transplant e.g dialysis and on-going patient management costs. This is done in the cost-benefit analysis of the soft opt-out scheme using Department of Health data – but which seemed somewhat dated (2005/06 prices). A more recent analysis using Welsh data might be an advantage.
8. The benefits of transplants were translated into Quality Adjusted Life Years (QALYs) – which is the accepted currency for assessing health gain – although the valuation of £60,000 for each QALY gained (again based on Department of Health estimates) does seem excessive when compared with the NICE QALY threshold of £20,000 - with increased valuations for end-of-life therapies.

9. It is important to state however that the economic issues are but one feature that need to be taken into consideration in assessing this particular policy initiative – and economic appraisal cannot do justice to all of the factors that need to be included in any evaluation of this policy.

Professor Ceri J. Phillips

January 2013

Agenda Item 7

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

Cynulliad
Cenedlaethol
Cymru

National
Assembly for
Wales



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.