

Health and Social Committee

Human Transplantation (Wales) Bill – Stage 1 consideration

To: Health and Social Care Committee
From: Legislation Office
Meeting date: 5 December 2012

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 Human Transplantation (Wales) Bill ('the Bill').

Background

3. On 20 November 2012, the Business Committee referred the Bill to the Health and Social Care Committee ('the Committee'), with a reporting deadline of 22 March 2013.
4. On 3 December 2012, Lesley Griffiths AM, Minister for Health and Social Services, introduced the Bill and Explanatory Memorandum. She also made a statement in plenary on 4 December 2012.
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 May/June 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 to increase the number of organs and tissues available for transplant by introducing a soft opt-out system of organ and tissue donation in Wales, by reference to:

1. The individual provisions set out in the Bill—
 - Section 2, relating to the promotion of transplantation,
 - Section 3, relating to lawful transplantation activities,
 - Sections 4–8, relating to consent,
 - Sections 9–11, relating to offences,
 - Sections 12–20, which make general provision.
2. Any potential barriers to the implementation of these provisions and whether the Bill takes account of them.
3. 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)).
4. The appropriateness of the powers in the Bill for Welsh Ministers to make subordinate legislation (as set out in Part 1, paragraph 91 of the Explanatory Memorandum, which contains a table summarising the powers for Welsh Ministers to make subordinate legislation).

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 22 March 2013.
11. The reporting deadline allows 10 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.

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 **Annexe 1**.
- **Oral evidence**
Invite key stakeholders to give oral evidence at future meetings (alongside the consultation exercise). A provisional list of witnesses drawn from the relevant sectors is attached at **Annexe 2**.

13. The reporting deadline allows for a 6-week consultation period, from 7 December 2012 to 18 January 2013.

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 (Annexe 1);
- the provisional list of witnesses (Annexe 2).

Annexe 1

Suggested persons/organisations to contact for written evidence:

Local Health Boards/NHS Trusts
Welsh Ambulance Service
Public Health Wales
WHSSC
Clinical Leads for Organ Donation
Specialist Nurses for Organ Donation
NHS Blood and Transplant Board
Retrieval Teams
All Wales Renal Network
Board of Community Health Councils
Critical Care Networks
Cardiac Networks
The All Wales Organ and Transplant Advisory Group
Royal College of Surgeons
Royal College of Physicians
British Transplant Society
College of Emergency Medicine
Welsh NHS Confederation
Royal College of Anaesthetists
Royal College of General Practitioners
Royal College of Nursing
Royal College of Paediatrics and Child Health
Royal College of Pathologists
Royal College of Midwives
Royal College of Ophthalmologists
Royal College of Radiologists
Academy of Royal Colleges Wales
Faculty of Intensive Care Medicine
BMA
Coroners in Wales
Statutory Health Advisory Committees

Paediatric Intensive Care Society
Welsh Intensive Care Society
Kidney Wales
Welsh Kidney Patients Association
Transplant 2013

Diabetes UK
British Heart Foundation
Epilepsy Action
Welsh Mental Health Alliance
Children in Wales
Welsh Neurological Alliance
British Lung Foundation
DeafBlindUK
Action on hearing loss (formally RNID)
Learning Disability Wales
MIND Manager for Influence and Change
Shelter Cymru
Cystic Fibrosis Trust
British Liver Trust
Live Life then Give Life
Disability Wales
British Organ Donor Society
Kidney Research UK
Haemophilia Society
Patient Association
Human Tissue Authority
British Humanist Association
Donor Family Network

Cytun
Archbishop of Wales
Roman Catholic Church
Evangelic Alliance Wales
Free Church Council of Wales
Baha'I Faith
Buddhist Council of Wales
Buddhistcouncilofwales.org.uk
Shree Swaminarayan Temple
Hindu Temple Whitchurch
Reform Judaism
Muslim Council for Wales
Access for Black Children with Disabilities
African Community Centre
Barnardos Neville Street Project
Black Association of Women Step Out
Black Voluntary Sector Network Wales (BVSNW)

Cardiff Gypsy and Traveller Project
Cardiff Traveller Education Service
Ethnic Youth Support Team
Minority Ethnic Womens Network Wales
North Wales Equality Network
Race Equality First
SEWREC
Somali Integration Society
Somali Progressive Association
South East Wales Race Equality Council
Swansea Bay Race Equality Council
Taha Idris
Tai Pawb
Henna Foundation
Diverse Cymru
Valleys Equality Council
Wales Strategic Migration Partnership
Welsh Refugee Council

Children's Commissioner
Older Peoples Commissioner
Equality and Human Rights Commission
Welsh Language Commissioner
Welsh Independent Healthcare Association
Welsh Local Government Association
One Voice Wales
CBI Wales
Wales Audit Office
Police Forces in Wales
Trade Unions

Responded to Welsh Government Consultation

Prof Ceri Phillips – Swansea University
Prof John Saunders – Organ Donation Committee, Neville Hall Hospital and Chair of Royal
College of Physicians Committee on Ethical Issues in Medicine
Dr Abdalla Yassin Mohamed – Director of Cardiff's Islamic Social Services Association
Society for the Protection of Unborn Children
Baptist Union of Wales
Methodist Church in Wales

Orthodox Wales
Presbyterian Church of Wales
Royal Pharmaceutical Society Wales
Llantrisant Fawr Community Council
Llanarmon yn Lal Community Council
Sealand Community Council
Llanelli Town Council
Wales Orthodox Mission
Synod Cymru of the Methodist Church in Wales
Llangathen Community Council
Faculty of Intensive Care Medicine London
Mold Town Council
Monmouth Baptist Church
Llangunnor Community Council
Cartrefi Cymru Friday Night Project
The Law Society
Faculty of Health, Sport and Science, The University of Glamorgan
Soroptimist International Port Talbot
Pembroke Town Council
NHS Centre for Equality and Human Rights
Information Commissioner
Health, Ethics and Law, University of Southampton
Christian Medical Fellowship
UK Donation Ethics Committee
SKLP Community Centre
India Centre
Albany Road Baptist Church
Presteigne and Norton Town Council



Annexe 2

Health and Social Care Committee

Suggested witnesses

Date of paper:

3 December 2012

This briefing has been produced by the Research Service for use by the Health and Social Care Committee.

For further information, contact Victoria Paris in the Research Service

Telephone ext. 8678

Email: victoria.paris@wales.gov.uk



Research
Service



Suggested witnesses

The purpose of this paper is to present the Committee with some suggested oral witnesses for the Stage 1 scrutiny of the *Human Transplantation (Wales) Bill*.

Healthcare providers

- **Welsh NHS Confederation** – The membership body representing all the organisations making up the NHS in Wales. Specifically **Clinical Leads on Organ Donation (CLOD)** and **Specialist Nurses for Organ Donation (SNODs)**.
- **Academy of Royal Colleges** – The Academy's role is to promote, facilitate and where appropriate co-ordinate the work of the Medical Royal Colleges and their Faculties for the benefit of patients and healthcare. The Academy comprises the Presidents of the Medical Royal Colleges and Faculties who meet regularly to agree direction.

Organ transplantation

- **NHS Blood and Transplant: Organ Donation and Transplantation (ODT) Directorate** – ODTs key role is to ensure that organs donated for transplant are matched and allocated to patients in a fair and unbiased way. ODT do not have a direct relationship with patients and do not provide hands on care. ODT manage the UK Transplant Registry and maintain the national NHS Organ Donor Register.
- **Human Tissue Authority (HTA)** – HTA is a watchdog that supports public confidence by licensing organisations that store and use human tissue for purposes such as research, patient treatment, post-mortem examination, teaching, and public exhibitions. The HTA has a role in making sure human tissue is used safely and ethically, and with proper consent.
- **British Transplantation Society (BTS)** – The BTS is the professional voice of transplantation in the UK, representing all the varied disciplines in transplantation including clinicians, nurses, pharmacists, scientists involved both in basic research and in histocompatibility laboratories, ethicists and other professions allied to medicine.



Ethics and human rights

- **UK Donation Ethics Committee (UKDEC)** – The UKDEC is an independent source of advice and guidance on ethical aspects of organ donation and transplantation. It aims to increase professional and public confidence in the ethical basis for decisions and processes in organ donation. The UKDEC is hosted by the Academy of Medical Royal Colleges.
- **Nuffield Council on Bioethics** – The Nuffield Council on Bioethics is an independent body that examines and reports on ethical issues in biology and medicine.

Faith and BME

- **Muslim Council for Wales** – The Council is an independent, inclusive umbrella organisation that represents the interests of Muslims in Wales.
- **South Wales Jewish Representative Council** – The Jewish Leadership Council is a Jewish charity which brings together the major British Jewish organisations to work for the good of the British Jewish community.
- **Inter–Faith Council for Wales** – The Council is an umbrella organisation which brings together many of the different faith and spiritual communities living in Wales.
- **Black Voluntary Sector Network Wales (BVSNW)** – BVSNW is an umbrella, membership organisation that actively represents, supports and promotes the interests of Black and BME communities and the BME Voluntary Sector in Wales.

Voluntary sector

- **Patient Concern** – collate patient feedback and use this evidence to campaign for improvements to health and social care services across the UK.
- **Wales Alliance for Mental Health** – The Alliance provides the collective voice of the national voluntary organisations in Wales working in the field of mental health.



Academics

Professor Ceri Phillips – Ceri Phillips is Professor of Health Economics and Deputy Head of School (Research) at Swansea University. He has undertaken commissioned work for a range of organisations, including the World Health Organisation, Welsh Government, Department of Health, Department of Work and Pensions and a range of health authorities and pharmaceutical companies. In 2009 he was appointed to the Bevan Commission by the then Minister for Health and Social Services to advise and oversee the new configuration and structure of NHS Wales. He is a member of the All Wales Medicines Strategy Group (AWMSG), and Vice Chair of its Medicines Group which makes recommendations to AWMSG. He has been involved in formulating and developing the Occupational Health Strategy for Wales. In addition, he has been a member of NICE Programme Development Groups on a range of public health issues. On the BBC programme *Week In Week Out* Professor Phillips stated that although there could be long term financial benefits to the opt-out system, such as savings on dialysis treatment for kidney patients, it could put added pressure on already struggling hospitals with regard to critical care beds and theatre time.

Professor John Saunders – John Saunders is a consultant who heads an organ donation committee at Nevill Hall Hospital, Abergavenny, and is the chair of the Ethics Committee for the Royal College of Physicians. On the BBC programme *Week In Week Out* the Professor also highlighted his concern about the additional pressure on intensive care units and that more investment in intensive care facilities would be needed. He was also concerned that having an opt-in register and an opt-out system has the potential to confuse patients, resulting in lower donation rates.

Professor John Fabre – John Fabre works at the Department of Hepatology and Transplantation, King's College London School of Medicine. He is a former chairperson of the British Transplant Society. He has stated that the opt-out legislation introduced in Spain was not the reason for the country's high donation rate and that there is no evidence changing the law will increase the donation rate.