






Hong Kong Patients' Voices  
香港病人政策連線

# Body Right: Scienti or Volenti? Patient's Perspective

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# International Alliance of Patients' Organizations

-  IAPO is a global alliance representing **276** patient groups in **71** countries across all disease areas and promoting patient-centred healthcare around the world
-  IAPO's **vision** is to see patients placed at the centre of healthcare.
-  IAPO's **mission** is to help build patient-centred healthcare worldwide

# International Alliance of Patients' Organizations

## POLICY POSITIONS:

Access to treatment

Biosimilar medicines

Clinical trials

Counterfeit medicines

Health technology assessment

Human Rights-Based Approach

Innovation

Non-communicable diseases

Patient involvement in policy

Patient-centred healthcare

Patient Engagement in Hospitals

Patient Info & Health Literacy

Patient safety

Priority medicines

Sustainable development goals

Universal health coverage

WHO reform



Working with industry

# International Alliance of Patients' Organizations



Healthcare must be **designed** and **delivered** to meet the needs and preferences of patients.

Greater patient responsibility and usage will lead to improved **quality of life**, a more **cost-effective system** and, ultimately, **better healthcare** for everyone.

# Patient-Centred Healthcare

-  In 2004, the concept of PCH was introduced globally through the IAPO
-  In 2006, all IAPO members signed a Declaration on PCH

# Patient-Centred Healthcare

-  To achieve PCH at every level in every community, the IAPO is calling for the support and collaboration of **policy-makers**, **health professionals**, **service providers** and **health-related industries** to endorse these Five Principles and to make them the centre of their policies and practice.
-  We call upon **all stakeholders** to provide the necessary structures, resources and training to ensure that the Principles outlined in this Declaration are upheld by all.

# IAPO Declaration 2006

## Five PCH Principles:

-  1) Respect
-  2) Choice and Empowerment
-  3) Patient involvement in Healthcare Policy
-  4) Access and Support
-  5) Information



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# Patient-Centred Healthcare



## Principle 1 – Respect



Patients and carers have a fundamental right to patient-centred healthcare that respects their **unique needs, preferences** and values, as well as their autonomy and independence.




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# Patient-Centred Healthcare



## Principle 2 – **Choice and empowerment**


-  Patients have a right and responsibility **to participate**, to their level of ability and preference, **as a partner in making healthcare decisions that affect their lives**. This requires a responsive health service which provides suitable choices in treatment and management options that fit in with patients' needs, and encouragement and support for patients and carers that direct and manage care to achieve the best possible quality of life. Patients' organizations must be **empowered to play meaningful leadership roles** in supporting patients and their families to exercise their right to make informed healthcare choices.

# Patient-Centred Healthcare

- 🌍 Principle 3 – **Patient involvement in health policy**
- 🌍 Patients and patients' organizations deserve to share the responsibility of healthcare policy-making through **meaningful and supported engagement** in all levels and at all points of decision-making, to ensure that they are designed with the patient at the centre. This should not be restricted to **healthcare policy** but include, for example, **social policy** that will ultimately impact on patients' lives.

# Patient-Centred Healthcare

## Principle 4 – Access and support

 Patients must have access to the healthcare services warranted by their condition. This includes **access to safe, quality and appropriate services, treatments, preventive care and health promotion activities**. Provision should be made to ensure that *all* patients can access necessary services, regardless of their condition or socio-economic status. For patients to achieve the best possible quality of life, healthcare must support patients' **emotional requirements**, and consider **non-health factors** such as education, employment and family issues which impact on their approach to healthcare choices and management.

# Patient-Centred Healthcare





## Principle 5 – Information



Accurate, relevant and comprehensive information is essential to enable patients and carers to make **informed decisions** about healthcare treatment and living with their condition. Information must be presented in an appropriate format according to health literacy principles considering the individual's condition, language, age, understanding, abilities and culture.

# Human Body

Body property can be divided into two types:

-  **Tangible** (visible) :  
organ, blood, tissue, bone, hair, skin etc.
-  **Intangible** (invisible) :  
DNA, blood type, genome, racial info, disease info  
(including STD), family info, personal background,  
criminal record, criminal evidence etc

# Why property right is important




-  Privacy
-  Sentimental value
-  Morality
-  Consensus
-  Respect
-  Religious reason
-  Social reason
-  Personal reason

# Example 1

- 🌐 A man in China had a disease with his leg
- 🌐 Doctor advised him that amputation of the leg must be carried out or he will die
- 🌐 The family members believed in what the doctor advised
- 🌐 But they (including the patient) would rather let the patient die than having the leg removed
- 🌐 They believe man should die in one piece



# Example 2

-  In November 2016, there were rumours that blood collected from Red Cross donation centres would be sent to the mainland China so that explained why RC was calling people for blood donation frequently.
-  Also rumours that lots of mainlanders give birth or receive operations in HK so more blood was used for them.
-  The RC clarified to the public that it was not the case and explained that the drop in number of donors was caused by other factors.

# Scienti vs Volenti



**Scienti**

Informed Decision & Knowledge



**Volenti**

Choice & Respect

# Summary

- 🌐 Legislation = passing of new law
- 🌐 New law relating to human life requires public consensus
- 🌐 Public consensus requires discussion within the society
- 🌐 Discussion leads to find out:
  - 🌐 What is the commonly acceptable value?



# Keri Young

- 🌐 Keri Young and her husband, Royce, made the difficult decision to carry their unborn baby girl to full term although the fetus was diagnosed with a terminal illness.
- 🌐 The Oklahoma couple, learned at Keri's 20-week ultrasound that their unborn daughter, named Eva, was suffering from anencephaly.
- 🌐 According to the CDC, anencephaly is a condition that causes a baby to be born without parts of the brain or skull. Almost all babies born with the condition die shortly after birth.

# Eva

- 🌐 "Continuing the pregnancy meant we would have mourn the loss of a child," she wrote. "We'd have to have a funeral... for a baby. OUR baby."
- 🌐 However, at a follow-up doctor's appointment Keri and Royce were told that if they continued with the pregnancy some of Eva's organs - like her heart valves, kidneys and liver - could be donated. The unborn baby's lungs could be donated for research.
- 🌐 "Eva will have life even though it will be short," Keri wrote. "She'll donate anything she can and do more in her time on earth than I ever will."



## 器官捐贈移植登錄中心

Tuesday at 12:30 PM · 🌐

陳冠妙生病時仍做志工，曾寫下心情「雖然不舒服，還有人生病承受更大的痛苦，不知生命何時會結束，更要把握隨時幫助人的機會，這樣到終點，我才能沒有遺憾。」




等腎救命不成捐肝救人 她是最美麗的美髮師 - 生活 - 自由時報電子報

[news.ltn.com.tw](http://news.ltn.com.tw)

# Web Sites

 HKPV – [www.hkpv.org](http://www.hkpv.org)

 HA – [www.ha.org.hk](http://www.ha.org.hk)

 IAPO – [www.iapo.org.uk](http://www.iapo.org.uk)

 Facebook: 香港病人政策連線 HKPV



Thank You J