

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

- 6 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.

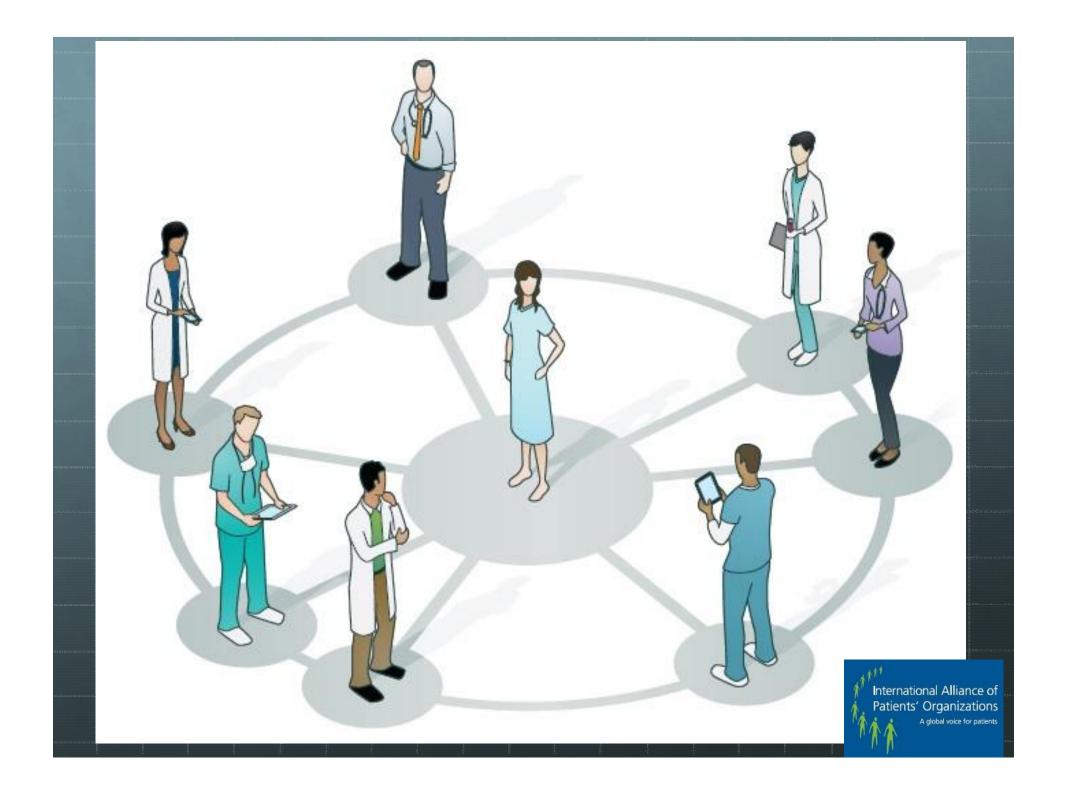
- In 2004, the concept of PCH was introduced globally through the IAPO
- In 2006, all IAPO members signed a Declaration on PCH

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





- 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.





- 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.

- 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.



- 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.



- 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

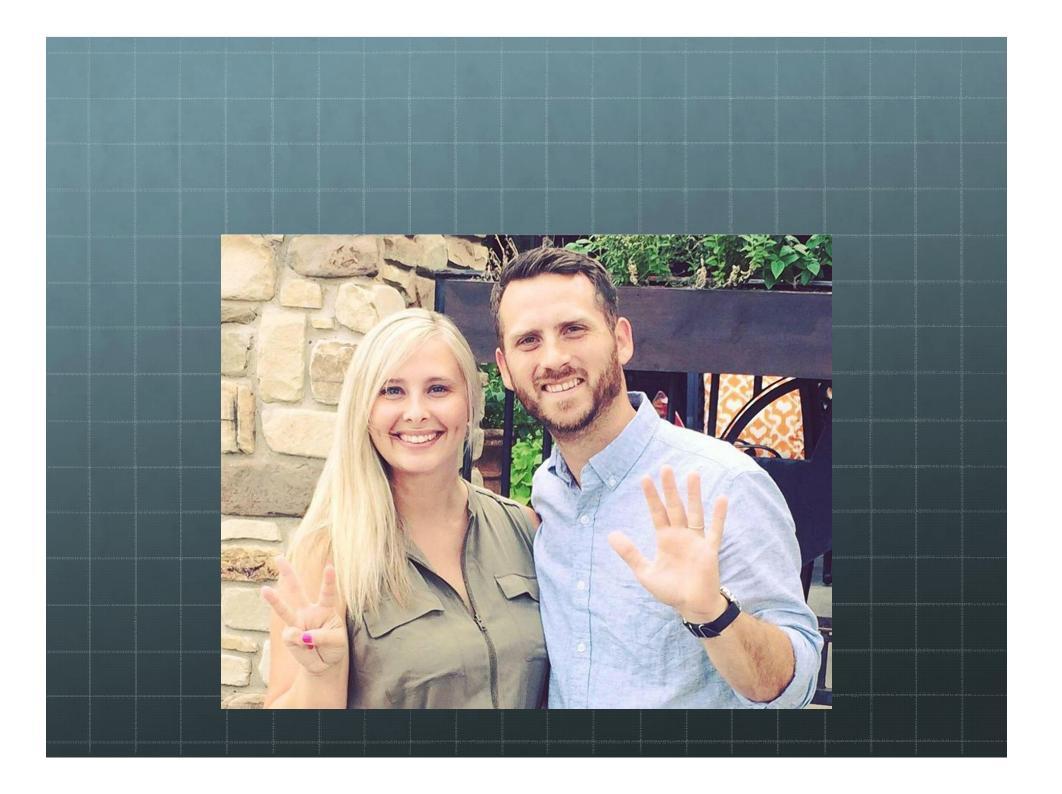
- In November 2016, there were rumours that blood collected from Red Cross donation centres would be sent to the mainland China so that explained why RC was calling people for blood donation frequently.
- Also rumours that lots of mainlanders give birth or receive operations in HK so more blood was used 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."



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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



- HKPV www.hkpv.org
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Thank You J