



*Speaker*

***First Plenary Session***  
**HEARING THE PATIENT'S VOICE IN  
HEALTH CARE DECISION MAKING IN ASIA**



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Consumer/Patient voice in drug  
reimbursement decision making

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## Why should the patient voice be heard?

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- Right to Health
    - UN Declaration on Human Rights
    - International Covenants on Rights
    - Patients have rights and Governments have duties
  
  - Moral Philosophy
    - Addresses the duties and responsibilities
    - How we should act towards each other & Govt to citizens
    - Provides guidance for legal interpretation
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## Constitutions, laws and health policies

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- Practical application of the right to health in each country
  - Aim for Universal Healthcare
  - Modified by social and economic reality
  - “Progressive realisation” is the way to get there
  - Influenced by societal expectations
  - Usually address population needs, equity, disadvantage
  - Should aim for consultation and participation in decision making at all levels in the health system
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## International views

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- International Alliance of Patients' Organisations
    - "Patients and patients' organisations deserve to share the responsibility for healthcare policy making through meaningful and supported engagement in all levels and at all points of decision-making"
  
  - World Health Organisation
    - "People-centred care includes attention to the health of people in their communities and their crucial role in shaping health policy and health services"
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## Moral frameworks

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- Autonomy
  - Consent
  - Respect
  - Do good
  - Avoid harm
  - Share risks and benefits
  
  - These need an inclusive process
  - Nothing about us without us
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## Patient's rights

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- The right to be heard at all levels
    - Strategic health planning
    - Local general service delivery
    - Specific service delivery issues, including drug reimbursement decisions
  
  - A practical way to try and balance the economic need to ration, with the patients' right to health
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## The dilemma and the challenge


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- Not every health need can be met
  - Prioritisation/Rationing is inevitable
  
  - Decision-making must be fair and inclusive
  - Must meet rights and the moral standards of society
  - HTA and economic assessments must be balanced with consideration of rights, equity & community values
  - The right to be heard reinforces patients' interests in the process
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## How are patients' voices heard and interests included?


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- In some jurisdictions, very well
  
  - e.g. NICE in the UK
    - Citizens' juries
    - Sophisticated engagement processes
    - Patient needs and interests clearly included in the practice of the organisation
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## How are patients' voices heard and interests included?

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- In some jurisdictions, very badly
  
  - New Zealand's Pharmac agency
    - Lip service to right to health
    - Excludes moral considerations of equity and community values
    - Focus entirely on (1) health outcomes, measured by cost per QALY, and (2) budget management
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## Power corrupts Absolute power corrupts absolutely

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- Pharmac set up with near absolute autonomy in order to make cost savings
  - The organisation is dominated by health economists and account managers
  - They reject active consideration of human rights or moral factors in their decision making
  - They have removed references to equity from their policy documents
  - They provide no space for formal patient input into their decisions
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## The lesson from this

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- Health economic assessments must be balanced with rights, equity and community values
  - Decision frameworks should specifically provide for this balance
  - Patient involvement in the process is the best way of ensuring the balance is maintained
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## Conclusion

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- It used to be that the greatest threat to patient interests in health were:
  - The unprincipled actions of health professionals, researchers or institutions
  - The threat of eugenic policies and practices
  
- Patient rights, ethics committees, and informed consent provide a lot of protection against those risks
  
- Today, the greatest threat to patient interests in the modern health system, is the budget managers and health economists who practice their arts without a moral compass

With best wishes to all of you from:  
John, Judith, Timothy and Hollie

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