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?

- 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

Constitutions, laws and health policies

- 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
International views

- 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”

Moral frameworks

- Autonomy
- Consent
- Respect
- Do good
- Avoid harm
- Share risks and benefits

- These need an inclusive process
- Nothing about us without us
Patient’s rights

➢ 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

The dilemma and the challenge

➢ 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
How are patients’ voices heard and interests included?

➢ 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

How are patients’ voices heard and interests included?

➢ 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
Power corrupts
Absolute power corrupts absolutely

- 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

The lesson from this

- 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
Conclusion

➢ 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