

Ethics in Drug Developmental Processes – Societal Perspectives

**Joint Medicines Policy
Conference 2011**

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- Dorian Gray pill
- Biologically-targeted
- Stops ageing
- No side effects
- \$100k per year

Ref: Prof Greg Mankiw NY Times 2009

Policy response – open market



Cost
Equity



Policy response – subsidise for all



Cost
Equity



Policy response – partial subsidy



Cost?

Equity?

- Old or young?
- Sick or well?
- Disadvantaged?
- Everyone the same?



Policy response – total ban



Equity

Cost

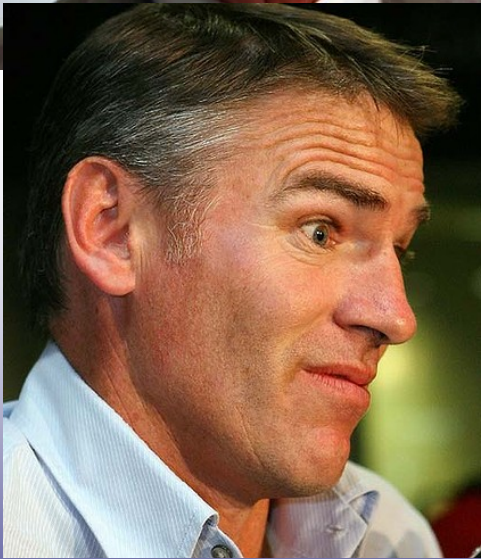


How to decide?

- Values and ethics
- Trade-offs –
opportunity costs
- No empirically ‘right’
answer
- ‘Right’ answer is the
one which best reflects
community
values/preferences



Who decides?



Evidence of the problem

- Consumer feedback
- Adverse events
- Reporting mechanisms
- Lack of transparency
- Post-market surveillance
- Poor communication
- Lags behind other areas
- Solutions ignored

“Jurors stated that the current distribution of health care does not adequately reflect the value they attached to equity”

The 7 Deadly Sins of 'Healthspeak'

- Sustainability
- Priorities
- Resource constraints
- Risk issues
- Data gaps
- Privacy
- Complexity/technical barriers





**Set-top
box**

VS

**New
Arthritis
medicine**



Trends in health care

1960s



1980s



2010s



Choice
Individualism
Targeting
Diversity
Interactive
Linkages

Values and principles

- Values and ethics issues
- No underlying principles
- Missed opportunity - NHHRC
- Community values
- Citizen focus – engage minorities/disadvantaged
- Ongoing process



Key questions

- How much do we spend on health?
- Where should we allocate resources?
- What proportion of costs should be shared?



Other processes: Consumer Reps

- Progress but still gaps
- Isolated
- Increased support
- Networking
- Role of peaks crucial
- Communication
- Research base



Consumer input: Future trends



- Pro-active
- Dynamic
- Interactive
- New technologies
- Multiple sources/processes



- Personalised
- Real-time
- Mobile

Future directions

- Citizens' Council - NICE
- Crowdsourcing
- Deliberative democracy
- Social media
- Microparticipation
- Prediction markets
- Wikis
- Market data



www.expertlabs.org

<http://cdd.stanford.edu>

www.nice.org.uk

www.activedemocracy.net

Dr Kathy Stiller AHR 2008 Vol 32 No 2
*It's not the evidence, it's the way
that you use it.*

Conclusion

- No crystal ball
- Principles and values
- Robust processes
- Cultures
- Inertia
- Point the thumb

