



Stanford - South Africa

Biomedical Informatics Program



Ethical issues for pharmacogenomics

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Trends in Ethics

(Knoppers & Chadwick)

Recent ethics literature has focused on key ideas that are informing current writing:

- Reciprocity--researchers are doing something for subjects, subjects are doing something for researchers
- Mutuality--information is shared for benefit of the community, not just individual benefit
- Citizenry--public understanding and engagement in science policy and priorities



Trends in Ethics II

- Universality--genome is universal, benefits and risks should be shared by all globally.
- Solidarity--individual must consider responsibility in decision making to community
 - Communal = common interests based on shared natural situation (e.g. insurance pool established to share unavoidable risk we have for bad luck)
 - Constitutive = interests in common because of current local circumstances (e.g. insurance rates are higher for those at higher risk)



Areas of discussion

- Concerns about genetic database privacy
 - Utility for research vs. security of subjects
 - Lin & Altman, SCIENCE 305, 9 July 2004, p 183.
- Concerns about discrimination
 - Health insurance
 - Employment
- Genuine consent for studies may be difficult in clinical setting
 - Patient feels vulnerable, wants to please doc



Areas of discussion II

- Stratification of patients by PGx may be an economic disincentive for drug development
- Danger of ethnicity used for profiling
 - Instead of genetic tests showing relevant SNPs
- Need for training health professionals and counselors to interpret results



Areas of discussion III

- Possibility of learning about risk for disease during PGx screening
 - Can it be treated? How likely?
- Can patients use a drug that requires genetic testing without the test?
 - Providers may be tempted to bypass tests
- Rights of family members to information vs. rights of individuals



Areas for discussion IV

- Orphan drug policies for drugs for “rare genotypes”?
- Preferential development of drugs for certain genotypes associated with “economically advantaged”

