



Genetic Screening and Informed Consent

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GENETIC SCREENING FOR DRUG METABOLISM AND GENETIC DISORDERS

药物代谢和遗传紊乱的遗传学筛查

Progress in human genetics has dramatically improved clinical knowledge in pharmacogenetics, predictive and preventive medicine; this knowledge needs to be put to work in culturally sensitive ways for individualized drug prescription and in individualized health risk prediction and prevention.

人类遗传学上的进展大大增强了遗传药理学、预测及预防医学方面的临床知识；这种知识应当在关注文化的基础上应用于个体化用药及个人健康危险的预测和预防。

Health is not just a status; rather the balanced result of health-literate and risk-competent care of one's own physical, emotional, and social wellbeing and wellfeeling, achieved in competent understanding, modification and enhancement of individual genetic, social and environmental properties, with the support of health care professionals and through equal access health care services, including information, predictive and preventive medicine.

健康不单纯是一种状态，而是在健康护理专家的帮助下，通过等效的包括信息、预测预防医学的健康保健服务途径，经过对个体的遗传、社会及环境属性的充分了解、改进与增强，个体的健康知识和危险承受能力可使其达到在身体上、情绪上及社会上的完满状态的平衡结果。

Patient oriented medical ethics [ren] and expertise [ji] need to be integrated to promote health literacy and communication-in-trust and cooperation-in-trust with all stakeholders involved in the care for health.

应当将以病人为主导的医学伦理学和专业技能综合起来，以在所有与医疗保健工作相关的人中促进健康文化的普及和信任基础上的交流与合作。

There is a right to know and an obligation to tell, if health risks are present or predictable. There is, however, only a moral, not a legal obligation to follow health care advice. Such a moral obligation becomes more pressing if health care costs are shared solidarily.

当健康危机存在或可预测时，患者有权利知情，医生有义务告知解释。但是否遵循医生所提的医疗建议是道德上的，而非法律上的义务。如果医疗费用由社会共同承担，那么这种道德上的义务就会变得更具有紧迫性。

Citizens are informational property owners of data concerning individual health status and health care. It is in their best interest to have Health Care Cards and to share information with professionals in a protected framework as data availability becomes as important as data protection.

公民是其个人健康状况和卫生保健信息的所有者。在数据可用性变得与数据保护同等重要的被保护框架内，享有医疗保健政策并与专家共享这些信息将会最大程度的使公民受益。

In complex issues of family ethics, privacy, disclosure, right not to know, and duty to know, diagnosed carriers would be the prime moral agents to make educated and responsible choices (a) to disclose, (b) to refuse disclosure of all or some information, and (c) to postpone hard choices in informing family members.

在处理有关家庭伦理道德、隐私权、曝光、不被告知权、知情权的复杂问题时，实施诊断的人是做出合理可靠选择的道德上的主要负责人 (a) 公开 (b) 拒绝公开所有或部分信息 (c) 延时通知病人家属的艰难选择

Culturally sensitive Informed Consent plus X 关注文化的知情同意和X

I.C. plus individual education

知情同意与个人教育

I.C. plus family or/and community education

知情同意与家庭或(和)社会教育

I.C. plus family or/and community health service

知情同意与家庭或(和)社会健康服务

I.C. plus info on benefits or no benefits

知情同意与利弊信息

I.C. plus extended health info and/or health service

知情同意与扩展的健康信息和(或)健康服务

It is time to replace an outdated informed consent model totally or in part by a contract model in which stakeholders such as probands, researchers and sponsors delineate moral and legal contractual rights and obligations.

现在应该采取合同形式完全或部分地取代过时的知情同意模式，在合同中所有相关人员，譬如(家系研究中尤指遗传疾病的家属史研究中的)先证者、研究者以及主办者阐述道义和法律上的契约权利和义务。